

AN EVALUTATION OF THE EFFECTIVNESS OF A STAFF – FOCUSED
INTERVENTION APPROACH FOR TREATING SLEEP PROBLEMS IN CHILDREN
WITH DEVELOPMENTAL DISABILITIES WHO LIVE IN RESIDENTIAL CARE

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Abstract

Sleep problems are highly prevalent among children and adolescents with developmental disabilities. As these sleep problems can significantly impact the overall wellbeing of an individual, the availability of effective intervention is imperative. Current research has identified a number of effective behavioural interventions to treat sleep problems in children and adolescents with developmental disabilities. These interventions have employed a number of antecedent and consequence-based strategies, as well as the use of parent group-training programmes. However, while there is evidence to support the use of behavioural interventions for sleep problems that are implemented by parents, there is a scarcity of research investigating these interventions by staff. As it is staff members, rather than parents, who support the proportion of children and adolescents with developmental disabilities living in residential care, it is important that a staff-focused intervention approach for sleep problems in this population be investigated. Despite empirical support for behavioural sleep interventions, research suggests that low levels of knowledge and attributional biases related to sleep problems may prevent parents from accessing treatment for their children's sleep problems. As these factors may represent treatment barriers among parents, it is important that these factors be assessed among residential staff. This thesis comprises two studies. Study One evaluated the impact of a group-delivered, staff-training workshop on the sleep knowledge and attributions held by 24 staff members working at a residential care facility. The brief, two-hour workshop provided staff members with information related to the prevalence, cause, assessment and treatment of sleep problems. Questionnaires administered both before and after the workshop were used to measure staff members' knowledge of sleep problems, as well as their attributions regarding locus, stability and controllability. Pre-and post-workshop data from questionnaires administered during Study One showed that the workshop increased the knowledge of 22 out of the 24 staff

members who took part. Furthermore, participation in the workshop altered staff members' attributions of sleep problems in this population to the extent that following the workshop, staff were more likely to attribute sleep problems to factors that were of external locus, stable (without treatment) and controllable. Study Two used single-case, multiple baseline design to evaluate the effectiveness of staff-delivered, Functional Behavioural Assessment (FBA)-informed, sleep interventions delivered to three children with ASD (11-17 years of age). These children were under the care of staff members included in Study One. Child participants presented with a variety of sleep problems, including sleep onset delay, curtain calls and early morning waking. Following a comprehensive assessment, individualized, FBA-informed treatment plans were developed by the research team and implemented by residential care staff. The effectiveness of interventions was measured via staff-reported sleep diaries. Study Two findings indicate that intervention resulted in reduced curtain calls and sleep onset in one participant, and reduced early morning waking in another. However, Study Two failed to find consistent improvements in the children's sleep outcomes in response to treatment, and treatment effects could not be measured for one participant due to the absence of intervention data. The present findings build on the paucity of research that has investigated the effectiveness of staff-implemented treatments for sleep problems in children with developmental disabilities living in residential care. The implications of these findings for the delivery of staff training and the implementation of behavioural sleep interventions within this setting are discussed. Future research into the effectiveness of a staff-focused sleep intervention programme, as well as the long-term impact of this intervention approach is warranted. Furthermore, given the complexity of these environments, future research should also explore factors that may facilitate the delivery of both group-training programmes and staff-implemented sleep interventions for staff working with children with developmental disabilities living in residential care.

Chapter 1

Introduction and Literature Review

Research indicates that between 50-80% of children who have a developmental disability experience sleep problems (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2012). The most common characteristics associated with sleep disturbance among children with developmental disabilities include sleep onset delay, nighttime awakenings, reduced total sleep time and behavioural bedtime difficulties (McLay, France, Blampied, Danna & Hunter, 2017). Sleep problems can have a profound impact on the wellbeing of a child and are unlikely to resolve without treatment (Meltzer & Mindell, 2007; Schrek, Mulick & Smith, 2004; Sivertsen, Posserund, Gillberg, Lundervold & Hsying, 2011). Behavioural interventions, such as modifications to sleep hygiene, extinction, scheduled awakenings, faded bedtime and use of reinforcement, are empirically supported strategies used to treat sleep disturbance in children with developmental disabilities (Cuomo et al., 2017; DeLeon, Fisher & Marhefka, 2004; Delmere & Dounavi, 2018; Durand, 2002; Sanberg, Kuhn & Kennedy, 2018; Vriend, Corkum, Moon & Smith, 2011; Weiskop, Richdale & Matthews, 2005). However, these interventions often require one-on-one time and cost-intensive support. An alternative, more cost effective approach to the treatment of sleep problems is group-training interventions, both with and without additional intervention support. This particular approach has been examined in research conducted among parents, with findings indicating that it is an effective way of treating sleep problems among both typically developing children and those with developmental disabilities (Austin, Gordon & O'Connell, 2013; Loring, Johnston, Gray, Goldman & Malow, 2016; Mao et al., 2017; Reed et al., 2009; Schlarb et al., 2011; Wade, Ortiz and Goreman, 2007).

Despite empirically supported treatment strategies for sleep problems, research shows that a number of parents of children with developmental disabilities and comorbid sleep problems do not access these strategies (Didden, Korzilius, Aperlo, Overloop & de Vries, 2002; Richdale & Robinsoon, 2004; Wiggs & Stores, 1998). Research suggests that low levels of knowledge about sleep problems, and attributional biases regarding the locus, stability and controllability of factors that underlie sleep problems are two variables that may prevent parents from seeking treatment (McDowall, Galland, Campbell & Elder, 2017; McDowall, Elder & Campbell, 2017; Owens, Jones & Nash, 2011; Schreck & Richdale, 2011).

A major limitation to extant research investigating sleep interventions for children and adolescents with developmental disabilities is that it has been conducted primarily with parents, and has evaluated interventions designed for children who reside in the family home. However, a number of children with developmental disabilities live in residential care facilities (Chen, Cullhane, Metraux, Park, Venable & Burnett, 2016), and a significant proportion of these children require interventions for sleep problems that are delivered by staff. Nevertheless, studies investigating the effectiveness of a staff-focused intervention approach for sleep problems in children with developmental disabilities residing in residential care are scarce. As such, it is important that the viability of this approach be investigated further.

The current study will attempt to build on existing literature by investigating a staff-administered treatment approach to sleep problems in children and adolescents with developmental disabilities. This aim will be achieved through two different, but related foci. First, this study will investigate the impact of a training workshop designed to educate residential staff about sleep and sleep problems in children with developmental disabilities. Secondly, following on from this training, Study Two will examine the effectiveness of staff-

delivered behavioural intervention for sleep problems in children with developmental disabilities for whom they care.

The following Chapter begins by providing a review of the existing literature regarding developmental disabilities and associated challenging behaviours. Following this discussion, it goes on to describe the nature, impact and possible causes of sleep problems among children and adolescents with developmental disabilities. A brief overview of empirically supported pharmacological and behavioural treatments is then provided. This overview includes research evaluating the effectiveness of behavioural interventions, both for sleep and other challenging behaviours, administered by staff working with children and adolescents with developmental disabilities. The concluding section identifies limitations to existing research into the treatment of sleep problems in young people with developmental disabilities and outlines the rationale for the current study.

Definition of Developmental Disabilities

Developmental disabilities are a group of conditions characterized by a severe and persistent delay in an individual's development, resulting in deviation from typical trajectories (Thambirajah, 2011). Developmental disabilities are associated with impairment in one or more developmental domains; including cognitive functioning, communication, social skills and/or motor ability (Odom, Blacher, Horner & Snell, 2007). This impairment must manifest prior to 22 years of age (Bornstein & Hendricks, 2010; Odom et al., 2007). Examples of developmental disabilities include: cerebral palsy, attention deficit hyperactivity disorder (ADHD), Down syndrome, autism spectrum disorders (ASD), intellectual disability and learning disorders (e.g. developmental dyslexia) (Olusanya et al., 2018; Thambirajah, 2011).

Prevalence of Developmental Disabilities

The prevalence rates of developmental disabilities among children vary. However, the World Health Organisation (WHO) estimates that worldwide, approximately 93 million children between 0-14 years of age have a moderate to severe developmental disabilities (Bornstein & Hendricks, 2013; WHO, 2011). In the United States alone, it is estimated that 15% of children and adolescents between the age of three and 17 years of age have a developmental disabilities (Boyle et al., 2011). Evidence suggests that the number of children and adolescents with developmental disabilities is rising, with numerous studies reporting a significant increase in the prevalence of ASD, ADHD, cerebral palsy, hearing loss and other pervasive developmental disorders (Boyle et al., 2011; Fombonne, Simmons, Ford, Meltzer & Goodman, 2001; Idrig et al., 2015; Kuo, Muo, Chang & Lin, 2015; Myers et al., 2019; Van Naarden Braun et al., 2015). The rise in prevalence rates is most notable for ASD, with one study observing a threefold increase between 2001 and 2011 (Idrig et al., 2015).

Physical and Behavioural Challenges Associated with Developmental Disabilities

In addition to cognitive, social and motor deficits, children and adolescents with developmental disabilities often present with co-occurring behavioural and medical conditions that affect their physical and emotional wellbeing (Al-Yagon, 2014; Joshi et al., 2010; Krakowiak et al., 2012; Strange et al., 2012). For example, rates of epilepsy, asthma, gastrointestinal and nutritional problems are higher among those with developmental disabilities compared to typically developing individuals (Krakowiak et al., 2012; Oeseburg, Groothoff, Reijneveld & Jansen, 2011; Soke, Maenner, Christensen, Spencer & Schieve, 2018; Somerville et al., 2008). The challenging behaviours that are commonly displayed by those with developmental disabilities can be split into those that are internalizing, and those that are externalizing. Internalizing behaviours have an internal focus, and include symptoms related to anxiety, depression, somatic symptoms and withdrawn behaviour, while

externalizing behaviours are those directed outward towards others, such as aggression, hyperactivity and delinquency (Mash & Wolfe, 2016).

Internalizing behaviour problems. The estimated prevalence of internalizing behaviours among children and adolescents with developmental disabilities varies significantly, with research reporting rates of between 11-84% (Al-Yagon, 2015; Strange et al., 2012; van Steensel, Bögels & Perrin, 2011; van Steensel & Heeman, 2017). Examples of internalizing behaviours commonly displayed by this population include emotional reactivity, suicidal ideation, suicide attempts, obsessions and mood disorders (Emerson & Einfeld, 2010; Gadow, DeVincent, Pomeroy & Azizan, 2005; Strange et al., 2012; van Steensel et al., 2011). The most frequently reported internalizing behaviours, however are anxiety and depression (Bauminger, Solomon & Rogers, 2010; Green, Gilchrist, Burton & Cox, 2000; Meyer, Mundy, Van Hecke & Durocher, 2006). These internalizing behaviours are displayed at significantly higher rates by children with developmental disabilities compared to those who are typically developing (Emerson & Einfeld, 2010; Green et al., 2015; Miller, Taylor, Hinshaw & Carter; Cairney, Rigoli & Piek, 2012; Strange et al., 2012).

Externalizing behaviour problems. Externalizing behaviour problems are often observed in children and adolescence with developmental disabilities, with reported prevalence rates ranging between 20-85% (Baker, Blancher, Crnic & Edelbrock, 2012; Emerson, 2003; Koskentausta, Iivanainen & Almqvist, 2007; Shea, Payne & Russo, 2018; Totsika, Hastings, Emerson, Lancaster & Berridge, 2011). Some researchers have suggested that the communication difficulties often experienced by this population may contribute to the development of challenging behaviours, as these children struggle to express themselves verbally (Martinez, Werch & Conroy, 2016; Matson, Wilkins & Macken, 2008; Shea et al., 2018). Common examples of externalizing behaviours displayed by individuals with developmental disabilities include delinquency, hyperactivity, aggression, defiance,

destruction of property and stereotypy (Al-Yagon, 2015; Bailey, Totsika, Hastings, Hatton & Emerson, 2019; Dekker & Koot, 2003; Emerson, 2003; Totsika et al., 2011). Rates of externalizing behaviours are consistently elevated among both children and adolescents with developmental disabilities compared to their typically developing counterparts (Al-Yagon, 2015; Bailey et al., 2019; Baker et al., 2012; Baker, Neece, Fenning, Crnic & Blacher, 2010; Emerson, 2003; Emerson & Einfeld, 2010; Emerson & Hatton, 2007).

Sleep Problems in Children with Developmental Disabilities

One of the most common challenging behaviours reported by parents of children with developmental disabilities are sleep problems (Joshi et al., 2010; Krakowiak, et al., 2012; Maskey, Warnell, Parr, Conteur & McConachie, 2012; Matson & Goldin, 2013).

Prevalence of sleep problems in children with developmental disabilities. Recent research estimates the prevalence of sleep disturbance among children with developmental disabilities to be between 50-80% (Boban, Leondard, Wong, Wilson & Downs, 2017; Goldman et al., 2011; Krakowiak et al., 2012; Mannion, Leader & Healey, 2005; Moss, Gordon & O'Connell, 2014; Richdale & Schreck, 2009; Singh & Zimmerman, 2015). These rates are noticeably inflated when compared to typically developing children, where prevalence rates of sleep problems are reported to range between 26-32% (Baker, Richdale, Short & Gradisar, 2013; Carotenuto, Esposito, Cortese, Laino & Verotti, 2016; Kelmanson, 2017; Quine, 2001; Richdale, Francis, Gavidia-Payne & Cotton, 2000; Teng, Bartle, Sadeh & Mindell, 2012). This observation remains consistent across numerous developmental disabilities, including ASD, developmental dyslexia, Down syndrome, William's Syndrome, Rett Syndrome and cerebral palsy (Boban et al., 2017; Carotenuto et al., 2016; Kelmanson, 2017; Goldman et al., 2009; Krakowiak et al., 2012; Stores & Stores, 2013; Tietze et al., 2012). Compared to their typically developing counterparts, children with developmental

disabilities commonly display longer sleep onset latencies, more nocturnal awakenings, decreased sleep efficiency and higher levels of daytime fatigue (Goldman et al., 2011; Krokowiak et al., 2012; Limoges, Motttron, Boldue, Berthiaume & Godbout, 2005).

Categories of sleep problems. The most common forms of sleep disturbance reported in children with developmental disabilities fall into three categories: (1) parasomnias; (2) dyssomnias; and (3) sleep problems arising from physical illness or psychological disorder (American Academy of Sleep Medicine, 2014; Krakowiak et al., 2012).

Parasomnias. Parasomnias are physical or experiential events that occur while the child is asleep (Thorpy, 2012). These events can present as abnormal behaviours, movements, emotions, dreaming, autonomic nervous system functioning or perceptions (Thorpy, 2012). Parasomnias can occur during both rapid eye movement (REM) and non-REM stages of sleep. Events that typically appear during REM sleep include sleep paralysis, nightmare disorder and dream enactment, (Olsen, Boeve, & Silber, 2000; Thorpy, 2012). Parasomnias that occur during non-REM sleep are typically associated with arousal and include confusional arousals, sleep walking and night terrors (Krakowiak et al., 2012; Thorpy, 2012). It is common for individuals to experience more than one parasomnia, and they often occur alongside other sleep disorders such as obstructive sleep apnea (Thorpy, 2012).

Dyssomnias. Dyssomnias are a cluster of sleep problems related to the initiation and maintenance of sleep, and represent the most commonly reported forms of sleep disturbance experienced by children with developmental disabilities (American Academy of Sleep Medicine, 2005; Krakowiak et al., 2012; Richdale & Schreck, 2009). Due to the nature of this cluster of sleep problems, they typically involve extended periods of nocturnal wakefulness and insufficient periods of nocturnal sleep (Thorpy, 2012). Behavioural

dyssomnia in children can be separated into dyssomnia related to (1) excessive time in bed, (2) sleep associations (i.e. requiring certain conditions to fall asleep) and (3) limit-setting (e.g., when children challenge bed-time instructions or expectations) (Meltzer, 2010; Owens & Mindell, 2011; Owens & Moore, 2017; Thorpy, 2012). Examples of dyssomnias typically presented by those with developmental disabilities include delayed sleep onset, early morning waking, irregular sleep-wake patterns, prolonged night awakenings and/or bedtime resistance (Deliens et al., 2015; Krakowiak et al., 2012; Owens & Mindell, 2011; Richdale, 2013; Richdale & Schreck, 2009; Singh & Zimmerman, 2015; Spruyt & Gozal, 2011; Stores & Stores, 2013; Vriend et al., 2011).

Course of Sleep Problems in Children with Developmental Disabilities

Sleep problems in children with developmental disabilities are unlikely to resolve without treatment (Deliens et al., 2015; Richdale, 2013; Richdale & Schreck, 2009). Thus, if left untreated, sleep problems experienced during childhood commonly persist into adolescence and even adulthood (Baker & Richdale, 2014; Baker, Richdale et al., 2013; Goldman, Richdale, Clemons & Malow, 2011; Limoges, Mottron, Bolduc, Berthiaume & Godbout, 2005; Øyane & Bjorvatn, 2005; Richdale & Robinson, 2004). Prevalence rates for sleep disturbance among adolescents with developmental disabilities range between 63-87% (Cortesi, Giannotti, Ivaneko & Johnson, 2010; Lanberg, Molitor, Oddo, Eadeh, Dvorsky & Becker, 2020; Hodge, Carollo, Lewin, Hoffman & Sweeney, 2014), with high levels of sleep disturbance, including daytime sleepiness, prolonged sleep latency and night waking, found among samples of adolescents with ADHD, ASD, Rett's syndrome and Williams syndrome (Baker & Richdale, 2015; Boban et al., 2017; Goldman et al., 2011; Goldman et al., 2009; Lanberg et al., 2020).

The type of sleep disturbance typically experienced by individuals with developmental disabilities changes over the course of childhood and adolescence (Carskadon, 2002; Goldman, Richdale, Clemons, & Malow, 2012; Santrock, 2014). For example, a study conducted by Goldman and colleagues (2012) examined the sleep characteristics of 1,859 children between three and 18 years of age, who were diagnosed with ASD. Participants were grouped into four categories: those that were younger than five years old, those between five and seven years old, those between seven and 11 years old, and those who were greater than 11 years old. Results showed that while the total sleep problem score did not differ significantly between age groups, the type of sleep disturbances reported by parents did. Findings indicated that parents of young children were more likely to report problems such as sleep anxiety, bedtime resistance, night wakings and nightmares. However, parents of adolescents were more likely to report problems of insomnia, such as difficulty initiating sleep, insufficient sleep and daytime sleepiness.

It is likely that a combination of environmental and biological factors explains these age-related changes in sleep patterns (Carskadon, 2002). Research indicates that during adolescence, individuals experience a shift in their biological clock (Crowley, Acebo & Carskadon, 2007; Crowley et al., 2014; Carskadon, 2002). More specifically, the secretion of melatonin and the resulting period of sleepiness occur approximately one hour later in older adolescents compared to young adolescents. As a consequence, they are likely to have difficulty falling asleep until later at night (Santrock, 2014). Other factors that may explain the change in type of sleep problems experienced between childhood and adolescence include greater academic obligations, increased social activity, reduced parental influence on bed times, and earlier school start times (Carskadon, 2002; Crowley et al., 2007; Goldman et al., 2011; Santrock, 2014).

Impact of Sleep Problems

The presence of sleep problems can have significant negative secondary effects both on the individual themselves and the wider family context (DeVincent, Gadow, De-losh & Geller, 2007; Hollway & Aman, 2011a; Meltzer & Mindell, 2007; Richdale & Screck, 2009).

Impact on daytime functioning. Sleep problems have a significant impact on the daytime functioning and overall wellbeing of children and adolescents. Along with daytime sleepiness, disordered sleep has been associated with externalizing and internalizing behaviours in both typically developing children and those with developmental disabilities (Bruni et al., 2007; DeVincent et al., 2007; Goldman et al., 2011; Hollway & Aman, 2011; Paavonen, Heiskanen & Lahikainen, 2009; Richdale & Shreck, 2009; Vriend et al., 2011). For example, DeVincent and colleagues (2007) examined the relationship between sleep problems and psychiatric symptoms in 112 pre-school aged children diagnosed with a pervasive developmental disorder and 497 typically developing children from a community-based sample. The results showed that across both groups, children with sleep disturbance exhibited greater externalizing behaviours, such as symptoms of ADHD and oppositional defiant disorder, than those who slept well. Similar findings have been reported in individuals with other forms of developmental disabilities, including intellectual disability and ASD (Goldman et al., 2011; Richdale, Francis, Gavidia-Payne & Cotton, 2000; Richdale & Screck, 2009; Sikora, Johnson, Clemons & Katz, 2012; Vriend et al., 2011).

Sleep problems are also associated with high rates of internalizing symptoms, such as anxiety and depression, in both typically developing youth and those with developmental disabilities (Alfano et al., 2007; Alfano, Zakem, Costa, Taylor & Weems, 2009; Bruni et al., 2007; Hollway & Aman, 2011). To examine the association between the presence of sleep problems and symptoms of anxiety and depression, Alfano and colleagues (2009) conducted a study using a community sample of 175 children and adolescents. Results revealed the

presence of sleep problems to be significantly associated with both forms of internalizing symptoms. The positive relationship between sleep disturbance and internalizing symptoms is mirrored in studies using samples of children and adolescents with developmental disabilities, thus suggesting that the nature of the relationship between these two factors remains consistent regardless of diagnosis (Bruni et al., 2007; Hollway & Aman, 2011; Malow, Marzec, McGrew, Wang, Henderson & Stone, 2006).

Sleep problems also appear to share a relationship with severity of symptoms associated with developmental disabilities, whereby greater severity of symptoms is observed among those with sleep disturbance (Allik, Larsson & Smedje, 2006; Goldman et al., 2011; Hoffman et al., 2005; Lambert et al., 2016; Schreck, Mulick & Smith, 2004). For example, research has shown that children who experience sleep problems are more likely to display social and communication deficits, greater sensitivity to stimuli, more significant delays in speech development, and higher levels of restricted and repetitive behaviours (Gabriels, Cuccaro, Hill, Ivers & Goldson, 2005; Goldman, Surdyka, Cuevas, Adkins, Wang & Malow, 2009; Taylor, Schreck & Mulick, 2012; Veatch, Sutcliffe, Warren, Keenan, Potter & Malow, 2017).

Unfortunately, these studies do not establish a causal relationship between sleep disturbance and an individual's daytime functioning. As a result, we cannot identify whether, *ceteris paribus*, sleep problems alone cause these observed outcomes, or whether they are produced by alternative, unidentified variables. Furthermore, it cannot be ruled out that the relationship between these factors is such that the severity of these symptoms in fact contributes to sleep problems. However, intervention studies conducted among typically developing youth do support the theory that sleep problems directly impact daytime behaviour (Becker et al., 2019; El Rafihi-Ferreira, Pires, & de Mttos Silves, 2019; Loring, Johnston, Shui & Malow, 2018). For example, following the implementation of a behavioural

sleep intervention, and resulting reduction in sleep disturbance, El Rafihi-Ferreira and colleagues (2019) observed an improvement in both internalizing and externalizing symptoms in preschool-aged children. The same improvements were not observed among participants assigned to the waitlist control group who did not receive the sleep intervention. These findings suggest that the alleviation of sleep disturbance may have resulted in an improvement in daytime functioning. Similar results were observed among adolescents (age 11-18years), who underwent a sleep education intervention (Loring et al., 2018). Following the intervention, and resulting reduction in sleep problems, adolescents exhibited improvements in daytime measures of anxiety, impulsivity, inattention and depression. Thus, while it is not possible to rule out a bidirectional relationship, this research does suggest that sleep problems contribute to internalizing and externalizing behavioural symptoms in both children and adolescents.

Impact on the family system. The impact of sleep problems in children and adolescents extends beyond the individual concerned. Research shows parental wellbeing and family functioning are also effected (Doo & Wing, 2006). For example, studies have found that parents of children with developmental disabilities and sleep problems tend to display poor sleep quality, increased risk of depression, and high levels of fatigue, stress, and marital discord (Doo & Wing, 2006; Hoffman, Sweeney, Lopez-Wagner, Hodge, Nam & Botts, 2008; Levin & Scher, 2016; Meltzer, 2011; Meltzer & Mindell, 2007). The impact of sleep problems on the welfare of siblings has also been evaluated. This research indicates that siblings of those with developmental disabilities and comorbid sleep problems display more behavioural difficulties than siblings of those without sleep problems (Schwichtenberg, et al., 2013)

Causes of Sleep Problems in Children and Adolescents with Developmental Disabilities

Sleep is a complex activity, influenced by a combination of physiology, the environment and learning (Bathory & Tomopoulos, 2017; Camerota, Propper & Teti, 2019; Hense et al., 2011; Stores, 2016). Therefore, there are numerous factors that may contribute toward sleep problems. Factors that underpin sleep problems are likely to vary across individuals, and thus should be viewed through a biopsychosocial framework, that includes biological, psychological and social factors (Richdale & Schreck, 2009).

Biological factors. Several biological factors may contribute toward sleep disturbance in those with developmental disabilities. Firstly, genetic abnormalities associated with certain developmental disabilities predispose some individuals to sleep disorders. (Richdale, 1999; Richdale & Schreck, 2009; Richdale & Wiggs, 2005). For example, research conducted by Nicholas and colleagues (2007) found that genes associated with the regulation of the biological clock, known as ‘clock genes’, are expressed abnormally in individuals with ASD. One hypothesis is that these genetic abnormalities alter the expression of neurotransmitters directly related to the sleep-cycle, such as serotonin and melatonin (Richdale & Schreck, 2009). Melatonin, which is synthesized from serotonin, plays a primary role in the regulation of the sleep-wake cycle, by signaling sleep onset (Zisapel, 2017). A number of studies have observed that melatonin levels among those with ASD are significantly lower than those seen in typically developing individuals (Kulman, Lissoni, Rovelli, Roselli, Brivio & Sequeri, 2000; Melke et al., 2008; Tordjman, Anderson, Picjard, Charbuy & Touitou, 2005). Such evidence supports the hypothesis that genetic abnormalities that impact on the circadian rhythm may contribute toward dyssomnias.

Other physiological abnormalities associated with developmental disorders can also contribute to disturbed sleep (Liu, Hubbard, Fabes & Adam, 2006). For example, epilepsy is reported in approximately 15-40% of children and adolescents with developmental

disabilities (Bandino, Garfinkle, Zickefoose & Hsieh 2014; Danielsson, Gillberg, Billstedt, Gillberg & Olsson, 2005; Zafeiriou, Kontopoulos & Tsikoulad, 1999). Research has identified a strong link between epilepsy and sleep disturbance, with studies showing that children and adolescents with epilepsy experience significantly higher rates of sleep problems than those without epilepsy (Cortesi, Giannotti & Ottaviano, 1999; Millichap, 2006). Research conducted by Newman and colleagues (2006), investigating sleep disturbance among children with cerebral palsy, also reported that epilepsy was the factor most strongly associated with sleep problems. There are a number of ways that epilepsy is thought to contribute toward sleep disturbance. For example, it is suggested that seizures during the night increase the rate of night wakings, while antiepileptic medication may increase the occurrence of parasomnias, such as nightmares (Lanigar, 2017).

Recent research has also indicated that pain, which is experienced on a daily basis by approximately 32-50% of children with developmental disabilities, may contribute to sleep disturbances among this population (Breau & Camfield, 2011; Breau, Camfield, Symon, Bodfish, McKay & Finley, 2003; Hemmingsson, Stenhammar & Paulsson, 2009). For example, Breau and colleagues (2011) found that parents who indicated that their child experienced pain regularly were also likely to report high levels of sleep problems, including night wakings, disordered breathing, and sleep-talking. These findings support earlier research, which identified pain as a strong predictor of sleep problems among children with physical disabilities (such as cerebral palsy and spina bifida) (Breau et al., 2003; Hemmingsson et al., 2009). Other, more specific physiological abnormalities commonly associated with developmental disabilities, such as narrowing of the airways, and sensory impairments (e.g. hearing and vision loss), which can result in lack of sleep-enhancing environmental cues, may also contribute to sleep problems (Hill et al., 2016; Kuroda et al., 2017; Richdale & Wiggs, 2005; Simpson, Oyekan, Ehsan, Ingram, 2018).

Psychological and behavioural factors. A number of psychological and behavioural factors can also negatively impact an individual's sleep (Hollway & Aman, 2011; Richdale & Wiggs, 2005). This includes internalizing and externalizing symptoms.

Internalizing behaviours. Rates of internalizing behaviours, such as anxiety, depression, suicidal ideations and mood disorders are elevated among those with developmental disabilities (Al-Yagon, 2015; Bailey et al., 2019; Baker et al., 2012; Baker et al., 2010; Emerson, 2003; Emerson & Einfeld, 2010; Emerson & Hatton, 2007). These behaviours have been positively associated with sleep disturbance in typically developing children and those with developmental disabilities (Alfano, Ginsburg & Kingery, 2007; Allik, Larsson & Smedje, 2006; Bruni et al., 2007; Hollaway & Aman, 2011; Hollaway, Aman & Butter, 2013; Malow, Marzec, McGrew, Wang, Henderson & Stone, 2006). For example, Hollaway, Aman and Butter (2013) evaluated the correlates and risk factors of sleep disturbance in 1,583 individuals, aged between two and 17 years of age, who were diagnosed with ASD. A regression analysis revealed that, among this large sample, the strongest predictor of disturbed sleep was individual's level of anxiety, as indicated by a strong, positive relationship between total sleep disturbance scores and scores on the Child Behaviour Checklist (CBCL) anxiety subscale. It is hypothesised that the increased psychological arousal and autonomic activity associated with anxiety disorders may contribute to sleep problems by preventing the child from falling asleep easily (Deliens, et al., 2015).

Externalizing behaviours. As previously stated, it is also common for children and adolescents with developmental disabilities to display high levels of externalizing symptoms, such as destruction of property, aggression, defiance, and emotional reactivity (Baker et al., 2012; Emerson, 2003; Koskentausta et al., 2007; Shea et al., 2018; Totsika et al., 2011). Such externalizing behaviours have been associated with sleep problems in both typically

developing youth, and those with developmental disabilities (Becker, Langberg & Evans, 2015; El Rafihi-Ferreira et al., 2019; Goldman, 2009; Hollway & Aman, 2011). A systematic review examining the relationship between problematic behaviours and sleep disturbance in children with ASD found that in 84% of cases, there was a significant, positive relationship between problem behaviours such as hyperactivity and aggression, and sleep problems (Hollway & Aman, 2011). More recently, a comparative study conducted by DeVincent and colleagues (2017) reported that compared to those without sleep problems, both children with and without Pervasive Developmental Disorder (PDD) who suffered from insomnia exhibited greater behavioural difficulties, such as symptoms of ADHD and oppositional defiant disorder than those who slept well.

Social and communication deficits. Social and communication deficits have also been associated with sleep problems in children and adolescents with developmental disabilities. The human circadian rhythm is regulated by both internal and external cues. External cues that support the synchronization of the sleep-wake cycle, known as Zeitgebers, include the natural light-dark cycle, and sound and social cues which are derived from interactions with other individuals (Deliens et al., 2015; Grandin, Allow & Abramson, 2009). Therefore, it is hypothesised that children and adolescents who show deficits in areas such as communication and socialisation may have difficulty perceiving or interpreting social cues that signal the time for sleep (e.g. meal times and caregiver-instructions regarding bedtime routine) (Deliens et al., 2015; Richdale & Schreck, 2009; Singh & Zimmerman, 2015). As a result, these children are more likely to experience problems associated with the initiation of sleep, such as bedtime resistance and sleep-onset delay (Deliens et al; Hollway & Aman, 2011; Hollway, Aman & Butter, 2013). In addition, children with social deficits may also be less able to express any pain or discomfort that may impede sleep (Singh & Zimmerman, 2015).

Taylor and colleagues (2012) found that among a sample of ten children aged between one and 10 years old with ASD, total hours of sleep was negatively correlated with communication problems and deficits in social skills. This finding has since been replicated by two separate, larger studies (Veatch, Sutcliffe, Warren, Keenan, Potter & Malow, 2017; Hollway et al., 2013). Research has also associated children's level of reciprocal social interaction with sleep problems (Malow et al., 2006). For example, Malow and colleagues (2006) observed that reciprocal social interaction scores were significantly lower for children classified as bad sleepers, compared to those categorized as good sleepers.

Additional aspects of ASD symptomology. Other characteristics commonly associated with ASD, such as restrictive and repetitive behaviours, may also contribute toward sleep problems. For example, a number of studies have found a positive correlation between restrictive and repetitive behaviours, such as stereotypy, and sleep disturbances, such as dyssnomnia and night-waking in children with ASD (Gabriels et al., 2005; Goldman, Surdyka, Cuevas, Adkins, Wang & Malow, 2009; Henderson, Barry, Bader & Jordan, 2011; Hollway et al., 2013). It is also common for children with ASD to struggle to adapt to changes in routine (Henderson et al., 2011). Thus, children with ASD may find it difficult to cope with any alteration to their bedtime and sleep routines, and are likely to become anxious or act out as a result. It is hypothesised that this heightened reaction then prevents children from successfully initiating sleep, as their level of arousal becomes too high (Hollway & Aman, 2011).

It is important to note that the majority of research regarding the causes of sleep problems has utilised a cohort, case-control or cross-sectional design. While these designs are useful for identifying the strength of the relationship between two factors (i.e. sleep problems and communication deficits), they do not permit cause and effect to be established. It is therefore possible that the relationship between these factors and sleep is bi-directional, in that the

symptoms may negatively affect children's sleep, while in turn the sleep problems exacerbate symptoms.

Social/environmental factors. Variables within the family home and the child's environment can also contribute toward sleep problems in children and adolescents with developmental disabilities (Richdale & Schreck, 2009). In order to develop a healthy sleep cycle, all children and adolescents need to adhere to appropriate sleep hygiene. Factors associated with sleep hygiene include consistent sleep scheduling, healthy sleeping habits and the provision of a sleep conducive environment (Meltzer & Crabtree, 2015). If these conditions are not met, then it can be difficult for the child to initiate and maintain sleep. For example, an environment that is too warm/cold, too light or too noisy can disrupt sleep and has in fact been found to increase the risk of sleep disorders in typically developing children and children with developmental disabilities (Galland & Mitchell, 2010; Spruyt, O'Brien, Cluydts, Verleye & Ferri, 2005). Additional environmental factors reported to increase the risk of sleep problems among children with developmental disabilities include co-sleeping (Liu et al., 2006; Mindell, Meltzer, Carskadon & Chevrin, 2008; Newman, Regan and Henesy, 2006), use of technology before bed (Cain & Gradisar, 2010; Hale & Guan, 2014) and an inconsistent bedtime (Cortesi et al., 2010; Meltzer & Crabtree, 2015; Mindell, et al., 2008; Moore, 2012).

Children's sleep may also be influenced by the family dynamic and overall level of functioning within the household. Those caring for children and adolescents with developmental disabilities face a number of additional challenges in everyday life, and as a result, typically experience higher levels of stress (Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003; Hayes & Watson, 2013). While the mechanisms that underpin the relationship are unclear, current research suggests that there is a positive correlation between household stress and sleep disturbance in children with developmental disabilities (Hanson &

Chen, 2010; Richdale & Schreck, 2009; Sadeh, Raviv & Gruber, 2000). For example, Sadeh and colleagues (2000) found level of family stress to be the strongest predictor of sleep quality in a sample of 140 children aged between seven and eight years of age. One explanation for this observation, proposed by Richdale (2013), is that the increased demands placed on the caregivers of those with developmental disabilities, and resulting levels of stress, may mean that they find it more difficult to maintain a consistent bedtime routine that is conducive to sleep.

To summarise, it is likely that sleep problems in children and adolescents with developmental disabilities are not caused by a single variable, but are instead the result of the complex interplay between biological, psychological and socio-environmental factors (Hollway & Aman, 2011; Richdale & Schreck, 2009). It is therefore important to consider all of these factors when investigating the causes of sleep problems, and when deciding the appropriate form of treatment.

A Behavioural Model of Sleep Problems

In addition to the factors stated above, sleep problems may also result from children failing to learn appropriate behaviours and routines that facilitate sleep (Blampied, 2013). This theory underpins the behavioural model of sleep disturbance, which is based upon operant behaviour theory. This behavioural model can be used to explain problems with the initiation and maintenance of sleep in children. Operant behaviour theory explains that the events immediately preceding a behaviour (the antecedents) and what happens after the behaviour has occurred (the consequences) influence the likelihood of a behaviour re-occurring (Skinner, 1969). According to operant behaviour theory, if the same set of factors consistently precedes the occurrence of a specific behaviour, they become ‘discriminative stimuli’, which act as a signal for the behaviour to occur (Blampied, 2013). Therefore, the

presence of discriminative stimuli increases the probability that a behaviour will recur under similar conditions. Consequences, on the other hand, can either increase or decrease the likelihood of a behaviour occurring, depending on whether these consequences are reinforcing or punishing (Skinner, 1969). Consequences that reduce the probability of a behaviour reoccurring are called ‘punishing consequences’, while those that increase its probability are labeled ‘reinforcing consequences’ (Skinner, 1969).

Research indicates that sleep cannot be altered by reinforcement or punishment (Blampied & France, 1993). Therefore, sleep itself is not classified as an operant behaviour. Instead, sleep should be viewed as a biobehavioural state that functions as a reinforcing consequence for the process of falling asleep (Blampied, 2013; Blampied & France, 1993). As such, it is the process of falling asleep, not sleep itself that represents the operant behaviour. This behaviour however, is the end of a much larger behavioural chain, comprising units of behaviours linked together by stimuli that act as both antecedents and consequences (Blampied, 2013). In the context of sleep, the operant behaviour chain begins with the start of bedtime preparations. For example, a child may have a bath, put on their pyjamas and brush their teeth before getting into bed. The behavior chain then ends with a period of behavioural quietude, which is necessary for the initiation of sleep (Blampied, 2013).

According to the behavioural model of sleep disturbance, there are two key requirements for a sleep conducive environment (Blampied & France, 1993). First, the operant chain leading from wakefulness to sleep must be controlled by appropriate discriminative stimuli. Discriminant stimuli can be external (such as lighting and temperature) or internal (such as level of tiredness), and may differ for each component of the chain (Blampied & France, 1993). Examples of stimuli that promote sleep include cool temperatures, dim lighting, quiet environments, comfortable bedding and fatigue (Blampied,

2013; Galland & Mitchell, 2010; Spruyt et al., 2005). As behavioural quietude is necessary for falling asleep, discriminative stimuli that keep overt motor activity, covert cognitive activity and perceptual stimulation to low levels also help to provide an appropriate environment for falling asleep (Blampied, 2013; Blampied & France, 1993).

Any changes to, or absence of appropriate discriminant stimuli within the bedtime routine delays sleep onset and thus contribute to problems in initiating sleep (Blampied & France, 1993). For example, if a child wakes in the night, and the discriminative stimuli that occurs at bed-time is no longer present, they can become distressed and unable to self soothe themselves (Blampied & France, 1993). This effect can be particularly problematic if parental presence is a discriminative stimulus for sleep, and can lead to parents being caught in what is known as a coercive behaviour trap. A coercive behaviour trap occurs when the parent's response to a child's behaviour (e.g. lying next to the child when they become distressed following a night waking), becomes reinforcing for not only the child, but also the parent themselves (Blampied & France, 1993). In this situation, the child's unsettled behaviour is positively reinforced by parent attention, while giving their attention provides parents with negative reinforcement, as it removes the child's distress (Blampied & France, 1993).

The second assumption is that the operant behaviour of falling asleep may be delayed if sleep-competitive behaviours exist within the larger behaviour chain. Behaviours that disrupt sleep include seeking parental attention, leaving the bedroom after being bid goodnight, or access to stimulating activities such as TV or electronic games (Didden, Curfs, van Driel & Moor, 2002). Such behaviours are often maintained by reinforcement (such as parental attention) and can also be under the control of discriminative stimuli (Blampied & France, 1993).

Thus, when looking at sleep from a behavioural approach, it is assumed that appropriate stimulus control is essential for good sleep, while inappropriate stimulus control can result in sleep problems (Blampied, 2013). Therefore, the promotion of positive sleep patterns requires a detailed analysis, and subsequent alteration of antecedents and consequences that maintain sleep interfering behaviour.

Interventions for Sleep Problems

The frequent and persistent nature of sleep problems observed among children and adolescents with developmental disabilities, and the negative secondary effects of such problems, means there is a strong need to identify effective treatment strategies. At present, both pharmacological and behavioural treatment approaches are used to treat sleep disturbance in this population (Guénolé, Godbout, Nicolas, Franco, Claustrat & Baleyte, 2011; Turner & Johnson, 2013).

Pharmacological Intervention

Due to the ease of implementation and immediacy of treatment effects, pharmacological approaches are often recommended as a treatment for sleep problems in children with developmental disabilities (Hollway & Aman, 2011b; Richdale, 2013). Indeed, research shows that children with developmental disabilities are the group for whom pediatricians most commonly prescribe medication as a treatment for sleep problems (Heussler et al., 2012). A number of pharmacological treatments have been used to treat sleep problems in children with developmental disabilities, including benzodiazepines, antihistamines and hormone treatment (Guénolé et al., 2011; Sajith & Clarke, 2007).

The most commonly prescribed pharmacological treatment is melatonin, a hormone naturally produced by the body that helps regulate the sleep/wake cycle (Dodge & Wilson,

2001; Hollway & Aman, 2011; Phillips & Appleton, 2004). Systematic reviews evaluating the effectiveness of melatonin provide support for its use. For example, to examine how efficacious melatonin therapy was in treating disordered sleep in individuals with ASD, Guérolé and colleagues (2011), examined twelve studies; including 4 case reports, 3 retrospective studies, 2 open-label clinical trials and 3 placebo-controlled trials. The results of these studies provided unanimous support for the use of melatonin among this population, with all twelve reporting an improvement in sleep problems. These findings were replicated in a more recent review conducted by McDonagh, Holmes and Hsu (2019). Unlike the earlier review however, McDonagh and colleagues included a range of sample populations, including typically developing children and adolescents, and those with comorbid disorders such as ADHD, ASD and neurodevelopmental disorders. Across all sample populations, melatonin was found to significantly improve sleep latency, sleep duration, and measures of nighttime awakenings. The greatest impact however, was observed in children with ASD, with this group showing the largest differences in sleep latency and sleep duration following melatonin treatment. Interestingly, the magnitude of effect resulting from melatonin therapy was found to be smaller among adolescent samples compared to that seen in younger children. This difference suggests that the effectiveness of melatonin therapy may decrease as individuals become older.

While there is evidence to support the use of melatonin, it is not always effective in treating problems such as early morning wakings, day-night sleep reversals and advanced sleep onset (Jan & Freeman, 2004). Moreover, the long-term effectiveness and safety of melatonin treatment is not well researched (Durand & Christodulu, 2004). All medications involve some risk of side effects. Presently, there is no evidence to suggest any major side effects associated with melatonin, though more mild symptoms, such as headache, confusion, cramps, rashes and daytime sleepiness have been reported (Guérolé et al., 2011; Jan &

Freeman, 2004; Richdale & Wiggs, 2005). Due to these limitations, behavioural interventions for sleep problems are often implemented alongside pharmacological methods, or as an alternative form of treatment.

Behavioural Interventions for Sleep Problems and Functional Behavioural Assessment

A number of behavioural strategies have been demonstrated to be effective in reducing sleep disturbance in children and adolescents with developmental disabilities. However, to maximize the effectiveness of these interventions, it is important that treatments are individualized, comprehensive and matched to the function of the behaviour (Blampied, 2013). One tool used for this purpose is FBA. FBA is a process that encompasses a range of assessment strategies, which are conducted prior to the formulation and implementation of intervention. Such strategies include indirect approaches such as interviews, questionnaires and rating scales, and direct observation (Blampied, 2013; Pfaller-Sadovsky, Arnott & Hutado-Parrado, 2019). The objective of FBA is to identify the antecedent and consequence variables that contribute toward or maintain problem behaviour (Ingram, Lewis-Palmer & Sugai, 2005; Jin, Hanley & Beaulieu, 2013; Pfaller-Sadovsky et al., 2019). This information is then used to form a hypothesis about the function of the behaviour and to construct a comprehensive treatment plan that is tailored to the individual (Blampied, 2013). Interventions constructed using FBA have proven to be more effective in treating challenging behaviours, such as self-injury, non-compliance and symptoms of ADHD, than behavioural interventions that did not use this approach (Hurl, Wightman, Haynes & Virues-Ortega, 2016; Ingram et al., 2005; Miller & Lee, 2003).

FBA is also an important component in the development of effective sleep interventions. Research has shown that FBA informed treatments effectively reduce sleep problems such as curtain calls and night-waking in children with developmental

disabilities (McLay et al., 2017; McLay, France, Blampied & Hunter, 2019). In the case of sleep-intervention, FBA is employed to identify antecedents and consequences that reinforce sleep-interfering behaviours (Hanley, Jin, Vanselow & Hanratty, 2014; McLay et al., 2019; McLay et al., 2017). The results of this assessment are then used to construct an intervention plan designed to modify reinforcing variables in such a way that a) reduces sleep-interfering behaviour and b) promotes sleep-conducive behaviours. To achieve these goals, behavioural sleep intervention plans may employ a number of antecedent- and consequence-based strategies.

Antecedent-based treatments for sleep problems. Empirically supported treatments that target antecedent factors include modifications to sleep hygiene, faded bedtime with and without response cost, visual supports and stimulus fading (Cuomo et al., 2017; DeLeon et al., 2004; Delmere & Dounavi, 2018; Durand, 2002; Sanberg, Kuhn & Kennedy, 2018; Vriend et al., 2011).

Sleep hygiene. Ensuring that children practice good sleep hygiene is often the first step in a behavioural sleep intervention (Sutton, Huws & Burton, 2019; Vriend et al., 2011). Sleep hygiene encompasses strategies that increase the number of activities and cues that prepare children for and promote sleep (Jan et al., 2008). Thus, a treatment approach that targets sleep hygiene will often involve implementing a consistent bedtime routine, creating a sleep-promoting environment (for example by reducing the amount of light and noise), and restricting stimulating activities prior to bedtime (Cuomo et al., 2017). Numerous studies have shown that sleep disturbance in children and adolescents, both with and without developmental disabilities, can be effectively treated using interventions that focus solely on improving the quality of the children's sleep hygiene (Delemere & Dounavi, 2017; Shokravi, Shooshtari & Shahhatami, 2016; Tan, Healey, Gray & Galland, 2012; Weiss, Wasdell, Bomben, Rea & Freeman, 2006). For example, in one study, 33 youths,

aged between 10 and 18 years of age completed a sleep hygiene programme that covered three main sleep hygiene categories: the sleep routine, sleep environment and eating and drinking habits before bedtime (Tan et al., 2012). Following the completion of the programme, significant improvements were observed for participants across all sleep measures, including the *Adolescent Sleep Hygiene Scale* (LeBourgeois et al., 2005), *Pittsburgh Sleep Quality Index* (Buysse, Reynolds, Monk, Berman & Kupfer, 1998), *Sleep Disturbance Scale for Children* (Bruni et al., 1996) and *Pediatric Daytime Sleepiness Scale* (Drake, Nickel, Burduvali, Roth, Jefferson & Pietro, 2003). These results indicate interventions that solely target children's sleep hygiene can improve children's sleep.

However, the effect of sleep-hygiene interventions on the sleep patterns of children with developmental disabilities is less researched, with studies producing mixed results (Jan, Owens, Weiss, Johnson, Waswell, Freeman & Ispiroglu, 2008). While there is little evidence to support the use of interventions that focus solely on positive sleep hygiene practices to treat sleep problems in this population, research does suggest that sleep hygiene is an important component that should be included in comprehensive behavioural sleep interventions (Jan et al., 2008; Singh & Zimmerman, 2015; Vriend et al., 2011).

Faded bedtime. The faded bedtime strategy is typically employed for sleep problems with a circadian component, such as delayed sleep onset and early morning waking (Cuomo et al., 2017). Faded bedtime is a process by which the child's bedtime is changed incrementally. Typically, the child's bedtime is initially pushed back, to a time at which the child is able to fall asleep within 15 minutes of going to bed (Cuomo et al., 2017). Once the child is consistently able to fall asleep within 15 minutes, the bedtime is incrementally brought forward to an earlier time. This routine is repeated until the desired bedtime is reached (Cuomo et al., 2017; Vriend et al., 2011). The establishment of a consistent wake-time, and the elimination of daytime sleep are also often included as part of this approach (Sanberg,

Kuhn & Kennedy, 2018). Previous research has shown that faded bedtime procedures can result in long-term improvements in sleep problems such as sleep onset latency and bedtime resistance among typically developing children (Cooney, Short & Gradisar, 2018). There is also evidence to suggest that this strategy is effective in treating sleep onset latency and sleep duration problems among children with developmental disabilities (Delmere & Dounavi, 2017; Vriend et al., 2011).

Faded bedtime with response cost. While there is evidence to support the use of faded bedtime in the treatment of sleep problems among those with developmental disabilities, treatment effects may be enhanced when this technique is paired with a response cost (DeLeon et al., 2004; Delmere & Dounavi, 2018, Piazza, Fisher & Sherer, 1997). The response cost aspect of the intervention involves removing the child from the bed if they do not fall asleep within 15 minutes, and then preventing them from returning to bed for up to one hour (Pizza & Fisher, 1991). Case-study research has shown faded bedtime with response cost to produce significant long-term improvement in the sleep quality of children with developmental disabilities (Moon, Corkum & Smith, 2010; Sanberg et al., 2018). For example, Sanberg and colleagues (2018) investigated the effect of bedtime fading with response cost on the sleep patterns of three children diagnosed with ASD. Following treatment, all three participants showed reductions in sleep problems, including the elimination of co-sleeping, reduced night-awakenings, shorter sleep-onset and reduced bedtime resistance.

Visual Supports. Due to associated social and communication deficits, children with developmental disabilities can find verbal and non-verbal cues difficult to interpret (Gray, 1998). At such times, the use of visual supports, such as social stories and Groclocks may be employed.

Social stories. Social stories are often used to treat challenging behaviours, including sleep problems, in children with developmental disabilities, and particularly those with ASD (Gray, 1998; Hutchins & Prelock, 2013; Karkhaneh et al., 2010; Kokina & Lee, 2010; Qi, Barton, Collier, Lin & Montoya, 2018; Scattone, Wilczynski, Edwards & Rabian, 2003). Social stories use visual prompts presented in the form of a short story to depict appropriate behavioural responses to certain situations (Gray, 1998). These stories are written from the perspective of the child and typically describe a particular activity, the setting of this activity, behavioural expectations associated with the activity, and the reinforcement for completing the activity correctly (Karkhaneh et al., 2010; Scattone et al., 2002; Gray, 1998). In the context of sleep problems, social stories depict the child's bedtime routine and other information about the treatment programme. While the use of social stories alone has not been found to produce significant changes in children's sleep, research shows that they can play a complementary role as part of multimodal behavioural treatments for sleep disturbance among those with developmental disabilities (Burke, Kuhn & Peterson, 2004; Malow et al., 2014; Moore, 2004; Test, Ritcher, Knight & Spooner, 2011).

Gro-Clock. A second visual tool that has been used to treat sleep problems in those with developmental disabilities is a 'Groclock'. A Groclock is an electronic device that changes appearance to help children discriminate between wake-time and sleep-time. For example, when it is time for the child to sleep, the Groclock will shine a blue light and show the symbol of a star. To signal that it is time for the child to get up in the morning, the clock will shine yellow and display a sun symbol. Little research exists on the effectiveness of Groclocks in treating child sleep problems. However McLay and colleagues (2019) found multimodal behavioural treatments that included the use of Groclocks to be effective in treating sleep problems among a number of children with ASD.

Consequence-based strategies for sleep problems. Treatment programmes that include consequence-based modifications are intended to alter the contingencies of reinforcement that maintain sleep-interfering behaviour. Consequence-based modifications include extinction and modified extinction, and the use of rewards (Etherton, Blunden & Hauck, 2016; Weiskop, Richdale & Matthews, 2005; Montgomery et al., 2004; Vriend et al., 2011; Reed et al., 2009). Each of these strategies is briefly described below.

Standard extinction. Extinction strategies for sleep disturbance are based on the assumption that sleep-interfering behaviours are being positively reinforced (e.g. by parental presence, access to preferred items etc.) (Etherton et al., 2016; Vriend et al., 2011). During an extinction intervention, these reinforcing variables are removed (Didden et al., 2002; Vriend et al., 2011). For example, if parental attention were reinforcing sleep-interfering behaviours such as crying, or curtain calls, a standard extinction intervention would require parents to ignore these behaviours, thus removing the reinforcement (Etherton et al., 2016; Vriend et al., 2011). Several studies have found that extinction-based procedures have a long-term, positive impact on the sleep quality of children with developmental disabilities. Such improvements include reductions in bedtime resistance, night waking and early morning waking (Montgomery et al., 2004; Reed et al., 2009; Vriend et al., 2011; Weiskop, Matthews & Richdale, 2001; Weiskop et al., 2005).

While effective, standard extinction strategies can be challenging for parents, not least because the elimination of reinforcement may trigger a Post-Extinction Response Burst (PERB). A PERB occurs when the implementation of an extinction strategy temporarily increases the variability, frequency and intensity of challenging behaviours, such as crying (France & Blampied 2005; Richdale & Wiggs, 2005; Vriend et al., 2011). Parents can find this change in behaviour distressing, and for this reason find it extremely challenging to implement standard extinction strategies (France & Blampied, 2005; Vriend et al., 2011).

Modified extinction. In an attempt to increase the social validity of extinction procedures, modifications to the standard extinction model have been suggested. These suggestions include graduated extinction, minimal check and faded parental presence (Singh & Zimmerman, 2015; Vriend et al., 2011).

Graduated extinction. Graduated extinction is a technique that involves gradually removing the reinforcement for sleep interfering behaviours (Mindell, Kuhn, Lewin, Meltzer & Sadeh, 2006; Singh & Zimmerman, 2015; Vriend et al., 2011). For example, in a situation where the child's sleep interfering behaviours are being reinforced by parental attention, a graduated extinction procedure may involve the parent incrementally increasing the amount of time that they remain outside the bedroom (Etherton et al., 2016; Owens, France & Wiggs, 1999; Vriend et al., 2011). The overall goal of this procedure is to slowly teach children how to self-soothe themselves until they are able to do so without parental presence (Mindell et al., 2006). Research has shown graduated extinction to be effective in treating sleep problems among typically developing children, and a number of studies have found this strategy to reduce sleep problems such as bedtime resistance and co-sleeping among individuals with ASD (Durand et al., 1996; Howlin, 1984; Montgomery, Stores & Wiggs, 2004; Moore, 2004; Richdale & Wiggs, 2005; Sadeh, Gruber & Raviv, 2002; Vriend et al., 2011).

Minimal check. During minimal check, parents are able to attend to their child at regular intervals (e.g. they may check on their child every 15 minutes) (France & Blampied, 2005; Owens et al., 1999). This approach is based upon the premise that parental attention is not contingent on the child's behaviour, but instead on time. Furthermore, when parents do attend to the child, they do so for only a set amount of time and provide minimal attention. For example, the parent may simply return the child to a comfortable sleeping position and offer little or no verbal assurance (France & Blampied, 2005). The use of minimal check has been found to be effective in reducing issues of sleep disturbance, such as night wakings in

both typically developing children, and those with developmental disabilities (France & Blampied, 2005; Matthey & Črnčec, 2012; O'Reilly, Lancioni & Sigafoos, 2004).

Faded parental presence. A second form of modified extinction is that of faded parental presence, also known as stimulus fading (France & Blampied, 2005; Sadeh, 1994; Matthey & Črnčec, 2012). Faded parental presence is a technique used in situations where parent attention is deemed to be reinforcing sleep interfering behaviours. During this procedure, parents are able to remain in the child's bedroom, either in a separate bed or chair, while the child is still awake (McLay et al., 2017). While in the room, parents will attempt to ignore their child's bids for attention, unless engagement is necessary for safety reasons (France and Blampied, 2005; McLay et al., 2017; Owens et al., 1999). Across the course of intervention, parents gradually increase the physical distance between themselves and their child until the child is able to fall asleep without a parent being present (Cuomo et al., 2018; Schreck, 2001; Vriend et al., 2011). It is suggested that having the parent still in the room reduces the likelihood of a PERB, whilst also minimizing reinforcement of sleep interfering behaviour (McLay et al., 2017). Faded parental presence has shown efficacy in treating sleep problems such as co-sleeping and night waking in typically developing children and those with developmental disabilities (France & Blampied, 2005; Hewitt, 1985; Howlin, 1984; McLay et al., 2019). Furthermore, France and Blampied (2005) found faded parental presence to be the graduated extinction strategy least likely to evoke a PERB.

Behavioural interventions have a number of advantages over pharmacological strategies. Firstly, behavioural approaches tend to be more socially accepted, as they offer effective and long-lasting treatment options without the risk of medication side effects and/or dependence (Vriend et al., 2011). Research suggests, for example, that parents prefer behavioural strategies for their children to sleep-enhancing medications such as melatonin (Kuhn & Weidinger, 2000). Secondly, the positive effects of behavioural interventions have

been found to extend beyond those experienced by the children themselves. For example, parent reported sense of competence, control and coping ability have all been found to increase as a result of implementing behavioural child sleep interventions (Wolfson, Lacks & Futterman, 1992). Furthermore, in the long run, behaviourally based sleep interventions have been found to improve marital satisfaction and parent sleep quality, and to reduce parental levels of anxiety, depression and stress (Kuhn & Weidinger, 2000; Vivian, 2018). However, behavioural interventions are most commonly administered individually, which, while effective, significantly increases the time commitment and financial cost of treatment (Austin, Gordon & O'Connell, 2013). High treatment costs have also been identified as a key barrier to treatment access, with research confirming that families are less likely to seek help for their child's sleep disturbance if they perceive it to be unaffordable and/or inaccessible (Owens, Palermo & Rosnen, 2002). Interventions administered in a group format are more affordable than individual interventions, with one study claiming group treatment to be six times more cost effective than those administered individually (Cunningham, Cremner & Boyle, 1995; Austin et al., 2013).

Group-Training Interventions for Sleep Problems in Children and Adolescents

A number of studies have evaluated interventions for sleep problems that incorporate a group-training component, either with or without the addition of intervention support (e.g. provision of treatment plans). Both of these intervention formats have been found to be effective in treating sleep problems among both typically developing children and adolescents and those with developmental disabilities (Schlarb, Liddle & Hautzinger, 2011; Wade, Ortiz & Goreman, 2007). For example, Wade, Ortiz and Goreman (2007) studied the effectiveness of a two-session, group parent-training programme on bedtime noncompliance in preschool aged children. During the training sessions, parents were provided with

information about how to implement consistent bedtime scheduling, graduated extinction and sleep hygiene. Researchers observed significant improvements in the children's bedtime compliance following this group intervention.

Sleep interventions including a parent-training component have also shown efficacy when conducted with parents of those with developmental disabilities (Austin et al., 2013; Reed et al., 2009; Moss, Gordon & O'Connell, 2014). For example, Austin and colleagues (2013) found the implementation of a group parent-training programme and subsequent intervention support to be effective in improving the sleep of preschool aged children with Pervasive Developmental Disorder. The programme was carried out over 15 weeks and included three, two-hour workshops. During these workshops, parents were provided with information regarding: typical sleep, positive sleep practices, types and causes of sleep disturbance, and strategies to reduce sleep disturbance. Following the completion of these workshops, parents then implemented individualized treatment plans, which were developed by programme facilitators in consultation with parents. The comparison of pre and post treatment data revealed that intervention produced significant reductions in children's overall level of sleep disturbance, daytime problem behaviours, night waking and bedtime resistance. Furthermore, the treatment approach showed high levels of social acceptability, with parents rating the programme highly in relation to ease of comprehension and usefulness.

Similar results have been observed among older children and adolescents with developmental disabilities (Moss et al., 2014). A study conducted using a sample of 26 children and adolescents, aged between eight and 17 years old, evaluated the effectiveness of a parent-assisted group-based treatment for sleep problems. The manualised treatment program consisted of a three-hour educational workshop, which included information about child and adolescent sleep, the impact of anxiety and technology on sleep, and cognitive behavioural strategies to target sleep problems. Parents were then provided with intervention

support in the form of individualized treatment programmes informed by a comprehensive sleep assessment, and required to implement these programmes. The interventions delivered by parents proved effective in treating children's sleep problems, indicated by a significant decrease in participant's scores on the *Children's Sleep Habits Questionnaire* (Owens, Spirito & McGuinn, 2000) following treatment.

Barriers to the Implementation of Behavioural Interventions for Sleep Problems in Children with Developmental Disabilities

Despite the availability of both pharmacological and behavioural interventions for sleep problems, research shows that a number of parents of children with developmental disabilities and comorbid sleep disturbance do not seek treatment (Didden, Korzilius, Aperlo, Overloop & de Vries, 2002; Richdale & Robinson, 2004; Wiggs & Stores, 1998). For example, Richdale and Robinson (2004) found that among their sample of parents of children with developmental disabilities and comorbid sleep disturbance, only 50% had sought treatment for their children's sleep problems. Factors such as lack of knowledge about sleep problems, and attributional biases regarding the locus, stability and controllability of sleep problems may act as barriers to the access and implementation of treatment for sleep problems within this population (Richdale & Robinson, 2004; Wiggs & Stores, 1998).

Parental knowledge of sleep problems. It is possible that a lack of parental knowledge regarding healthy sleep in children means that parents sometimes fail to recognise sleep problems. Findings from a study conducted by Richdale and Robinson (2004) support this notion, as despite parent-reports indicating that 60% of children in the study experienced sleep problems, many parents did not perceive their child's sleep to be problematic. Additional studies have also reported low levels of parental knowledge about sleep in both typically developing children and those with developmental disabilities (McDowall, Elder &

Campbell, 2017; McDowall, Galland, Campbell & Elder, 2017; Owens, Jones & Nash, 2011; Schreck & Richdale, 2011; Kanis, Schwerdtle, Kübler & Schlarb, 2015). For example, Owens, Jones and Nash (2011) found that when they administered a 10-item sleep knowledge questionnaire to a sample of 253 parents, only 4% of them were able to answer all 10 questions correctly and 35% answered fewer than half of the questions correctly. The most common incorrectly answered questions were those that referred to the average sleep needs of pre-school aged and school-aged children. For example, 52% of parents surveyed underestimated their child's sleep needs in terms of the recommended sleep duration for their child's age group. Owens and colleagues also noted that it was common for parents to lack knowledge regarding the negative impact that specific practices, such as watching TV before bed, can have on sleep. These findings were replicated in a more recent systematic review, which evaluated eight articles investigating parental knowledge of children's sleep (McDowall, Galland, Campbell & Elder, 2017). Results from this review indicated that parents typically have limited understanding of: a) the sleep needs of children (such as recommended sleep duration); b) appropriate bedtime routines; and c) characteristics of sleep problems (McDowall et al., 2017). As alluded to, if parents do not know how to distinguish between patterns of healthy sleep and sleep problems in children, they are unlikely to identify when they're child's sleep requires intervention. This theory explains how low knowledge of sleep problems may act as a barrier to accessing treatment.

Attribution theory. An additional theory is that the attributions parents hold about their children's sleep problems (i.e. their views on the cause(s) of their child's sleep problem), prevent them from seeking behavioural intervention (Mah & Johnston, 2008; Richdale & Robinson, 2004). This theory is based upon the cognition-emotion-attributional model proposed by Weiner (1980). Weiner's model categorizes the causal attributions parents make about their child's behaviour as either child-referent (beliefs about causes

related to the child), or parent-referent attributions (beliefs about causes related to the parents), and includes the dimensions of locus, stability and controllability (Weiner, 1980).

Locus refers to the extent to which individuals believe the behaviour is influenced by factors external or internal to the individual. Stability encompasses views on the permanency of the behavior, and controllability captures beliefs about whether the behaviour is under the individual's control (Weiner, 1980).

Applying this framework to children with developmental disabilities, research indicates that it is common for parents to attribute their child's problem behaviours to factors that are of internal locus, stable, and outside the child's control (i.e. not controllable) (Hartley, Schaldle & Burnson, 2013; Jonston & Freeman, 1997; Keenan, Wild & Espie, 2007; Whittingham, Sofronoff, Sheffield & Sanders, 2008; Woolfson, Taylor & Mooney, 2011). Such attributions can be problematic as they can influence parents treatment-seeking behavior as well as decisions regarding treatment selection (Dardennes et al., 2011; Keenan et al., 2007). For example, research indicates that parents who attribute their children's problem behaviour to factors that are of internal locus (such as their child's disability diagnosis), stable, and uncontrollable are more likely to rely on pharmacological intervention, and be less accepting of behavioural interventions than parents who believe that there is a learned component to the behaviour (Keenan et al., 2007; McDougall, Kerr & Espie, 2005)

Within the context of sleep problems, research has shown that parents of children and adolescents with a developmental disabilities often attribute their child's sleep problems to factors of internal locus, such as their diagnosis (Bessey, Coulombe, Smith & Corkum, 2013; Didden et al., 2002; Hartley et al., 2013; Keenan et al., 2007; McDougall et al., 2005). For example, Didden and colleagues (2002) examined sleep problems among a sample of 286 children with mild to profound intellectual disability. As part of their study, researchers asked parents what they believed to be the etiologies of their child's sleep problems. Results

showed that the most common cause suggested by parents was the child's diagnosis of intellectual disability. Results from qualitative research, conducted with nine families of children with Rett Syndrome identified similar findings, whereby parents attributed their children's sleep problems to the syndrome itself (McDougal et al., 2005). In addition, findings from this research indicate that parents of children with developmental disabilities are also likely to view their child's sleep problems as stable (stability), and therefore less likely to be resolved by intervention (i.e. uncontrollable) (Bessey et al., 2013; Hartley et al., 2013, Keenan et al., 2007).

Thus, the extent to which parents believe their child's sleep problems will respond positively to treatment may be directly influenced by their attributions regarding the locus, stability and controllability of causal factors. For example, in a sample of 58 parents of children with developmental disabilities who suffered from sleep disturbance, Keenan and colleagues (2007) found the attribution that sleep problems were caused by factors internal to the individual (i.e. internal locus) to be negatively correlated with the belief that their child's sleep problems could be treated (i.e. controllability). Therefore, the more strongly parents attribute their children's sleep problems to internal factors, such as the child's disability or temperament, the less likely they are to believe these problems are treatable, or can be controlled. The key issue is that if parents do not believe that sleep problems can be altered by treatment, they are unlikely likely to seek it. This assumption is supported by research that links coping mechanisms for 'managing' sleep problems, (as opposed to treating them), with parents who believe that their child's sleep problems are 'untreatable' (McDougall et al., 2005). It is important to bear in mind these findings when examining the treatment of sleep problems in children with developmental disabilities.

A Limitation of Current Research

Extant research provides substantial support for the use behavioural interventions in the treatment of sleep problems in children and adolescents with developmental disabilities. However, there is a major limitation to current literature on this topic. The studies evaluating the effectiveness of, and barriers to available treatments have focused almost solely on sleep problems experienced by children who live at home, and interventions that are administered by, and with, parents. Interventions that focus on parents assume that the child is in their parents' care. As a result of this assumption there is a proportion of children and adolescents with developmental disabilities that have been largely omitted from research relating to the treatment of sleep problems. This category consists of those who live in residential facilities, and are cared for not by parents, but by residential care staff.

Children and Adolescents with Developmental Disabilities in Residential Care

The challenges associated with developmental disorders can cause individuals with developmental disabilities to experience substantial functional limitations across numerous aspects of life, such as self-care, communication, mobility, self-direction, capacity for independent living, and the ability to sustain oneself economically (Burbachler et al., 2007). As a result, children and adolescents with developmental disabilities often require high levels of physical, behavioural and emotional support from their families (Chen, Cullhane, Metraux, Park, Venable & Burnett, 2016). When families are unable to provide the level of support required to care for their child, they may choose to place them in specialist residential care facilities, where they are cared for by appropriately qualified staff.

Factors influencing parents' decision for residential care. The decision to place a child into out of home care is an extremely difficult one for families to make (Mirfin-Veitch, Bray & Ross, 2003). A number of studies have examined the factors that influence parents'

decision making in this area. The results of such studies show that these factors are multisystemic, ranging from the characteristics of the parents and children themselves, to the wider community. A key theme associated with parents' decision to place their child in out-home care is feeling that they are unable to fulfill the care-giving tasks required by the child (Friedman & Kalichman, 2014; Hoystyn & Maes, 2007; Llewellyn, Dunn, Fante, Turbnull & Grace, 1999; Mirfin-Vietch et al., 2003). Qualitative data collected from parents who had placed their child into residential care revealed that the decision was heavily influenced by the fact that, as their child grew older, parents became unable to cope with the child's changing physical and behavioural needs and believed that the child would be better cared for in an out-of-home placement (Llewellyn et al., 1999; Mirfin-Vietch, et al., 2003). Parents also report that isolation from their own social support networks, as a result of the challenges associated with having a child with developmental disabilities, also contributed to this critical decision (Mirfin-Vietch et al., 2003).

Numerous studies have also found concern for the welfare of other children in the family to be a major factor contributing toward parents' decision to place their child into out-of-home care (Hoystyn & Mae, 2007; Llewellyn et al., 1999; Mirfin-Vietch et al., 2003; Friedman & Kalichman, 2014). Some of the specific concerns reported by parents included a feeling of guilt due to the lack of time and attention they were able to give to the other children in the family, and the isolation and embarrassment parents perceived the other children to experience as a result of having a sibling with developmental disabilities.

The associated financial strain that can result from providing such high levels of care may also play a role in the decision to place children in out-of-home care. The cost of caring for a child who has developmental disabilities is significantly higher than that associated with typically developing children (Parish et al., 2004; Xiong et al., 2010). Many parents of children with developmental disabilities also have to reduce the number of hours that they

work, or leave their jobs completely in order to care for a child with a disability (Khanna, Prabhakaran, Patel, Ganjiwale & Nimbalkar, 2015; Lindly, Chavez & Zuckerman, 2016; Spindler et al., 2017). Such loss of income can make it difficult for parents to meet the demands associated with parenting a child with developmental disabilities.

Number of children with developmental disabilities living in residential care.

There is little research documenting the number of children and adolescents with developmental disabilities living in out of home care (Friedman & Kalichman, 2014; Braddock, Emerson, Felce, & Stancliffe, 2001). However, a study conducted by Braddock and colleagues (2001) revealed that, in the year 2000, 5% of the United States formal residential sector was dedicated to children with disabilities, while the percentage of residential care provided to children with disabilities in Australia, England and Wales stood at 3% and 1% respectively. In New Zealand it was estimated that a total of 201 children and adolescents with developmental disabilities were living in residential care facilities in 2016 (Ministry of Health, 2017).

Children and adolescents living in residential care interact with the staff members at these facilities much more than they do with their own parents. Therefore, in such cases, parent-implemented interventions are not an appropriate form of intervention. Staff-focused interventions provide a logical alternative. However, a paucity of studies have investigated staff-implemented behavioural interventions to target sleep, or other behaviours in children and adolescents with developmental disabilities living in residential care.

Staff-Implemented Behavioural Interventions for People with Developmental Disabilities

The use of staff-training interventions among residential care staff is not well researched. However, there is growing evidence to support the use of staff-training

programmes that focus on enhancing the social and communication skills, and reducing challenging behaviours among, children and adolescents with developmental disabilities living in residential care (Ingersoll, Berger, Carlsen & Hamlin, 2017; Kossyvaki, Jones & Guldburg, 2016; Weinkauff, Zeug, Anderson, Ala'i-Rosales, 2011). For example, Weinkauff and colleagues (2011) evaluated the effectiveness of a training package delivered to a group of four staff members who cared for children with ASD. Over the course of the three-month training programme, trainers employed techniques such as verbal description, modeling, role-play, praise and feedback to teach staff-members behavioural strategies related to the domains of professionalism, ethics, building rapport, session and material management, and instructional procedures. These skills were grouped into three clusters, with skills in each domain becoming more complex within each cluster. Thus, the skill training was graduated, in that staff members could not proceed to the next cluster without mastering those in the current skill cluster. At the end of the three months, all four staff members mastered the criteria for all three clusters, demonstrating a consistent, increasing trend in skill demonstration scores. The staff that took part in the study stated that they felt the training was either effective, or very effective in improving their applied behavioural analysis implementation skills, and all four staff members were satisfied with their improvement following training. These findings suggest that behavioural intervention implementation strategies can be effectively taught to staff-members working with children with developmental disabilities in a group format. While the findings of this study are promising, it does not assess whether the skills that staff acquired translated to a change in child behaviour (i.e., whether the staff members included in this study able to use these newly acquired skills to alter the behaviour of the individuals they worked with).

A more recent study, conducted by Kossyvaki, Jones & Guldburg (2016) evaluated the efficacy of a staff-training programme administered to staff-members at a specialist

school for children with ASD (Kossyvaki, Jones & Guldberg, 2016). The aim of the study was to teach staff members to facilitate spontaneous communication in children with ASD. The intervention was conducted with three staff members and six children. Using the Video Interaction Guidance Intervention Model as a guide, researchers used video modeling, group discussion and role-play to teach staff members behavioural strategies that promoted communicative opportunities for the children in their care. In order to evaluate the effectiveness of these training sessions, video-recordings of the staff naturally interacting with the students were coded both before and after the training sessions. The comparison of these videos showed that staff significantly increased the number of times they used communication-promoting strategies post-intervention. Furthermore, the change in the staff's interaction style appeared to positively impact the children's communicative behaviour, with results showing that all six children significantly increased the number of times that they initiated communication following the intervention. All of the staff members who took part felt that taking part in the training sessions was a positive and empowering experience that promoted team bonding.

Lastly, Ingersoll and colleagues (2017) evaluated the effectiveness of a staff training programme designed to improve social functioning and challenging behaviours in 20 adolescents with ASD and intellectual disability living in residential care. Eight staff members underwent a two-week programme that trained them in reciprocal imitation training (RIT) (a behavioural intervention that targets social interaction). The training was provided by a third author who was a supervisor at the facility and had previously been trained in RIT. The components of the programme included the provision of information such as the goals and procedures of RIT, a review and discussion of videos that modeled RIT, and daily role-plays. Following the programme, staff members then administered RIT to adolescents. During the five-month treatment, adolescents in the treatment group received two, 10-minute

sessions three days a week. Following treatment, adolescents who received RIT displayed statistically significant improvements in social functioning, as indicated by the change in their scores on the *Matson Evaluation of Social Skills for Individuals with Severe Retardation* (MESSIER). Changes in participants' scores on the *Aberrant Behaviour Checklist* also indicated that adolescents exhibited significant decreases in challenging behaviour. The social validity of the procedure was rated highly by staff members, who reported that the intervention was easy to learn, and perceived the intervention to produce positive changes in the adolescent's behaviour, in particular the observed increase in their student's social responsiveness. While not specific to sleep, when viewed together these findings suggest that group intervention, implemented with staff members, is effective in not only improving staff members' knowledge and skill-set, but also in promoting behavioural change among children with developmental disabilities.

Staff-Implemented Behavioural Interventions for People with Developmental Disabilities and Sleep Problems

Only two studies have been undertaken to-date that evaluate the effectiveness of staff training programmes designed specifically to improve the sleep of individual's with developmental disabilities, living in residential care (Hylkema, Petitiaux & Rijksuniversiteit, 2011; Hylkema & Vlaskamp, 2009). A randomized control trial, conducted by Hylkema, Petitiaux and Rijksuniversiteit (2011), assessed the utility of a staff-training programme designed to treat sleep problems in individuals with intellectual disabilities. Forty-seven staff members from Dutch care facilities were randomly divided into two groups: a lecture-only group and a workshop group. Participants in both groups attended lectures that addressed the nature of sleep, the physiology and prevalence of sleep problems, sleep problems associated intellectual disability, sleep problems associated with other conditions (e.g. Autism, ADHD

and epilepsy), and finally, interventions that could improve sleep quality (such as sleep hygiene). Staff members assigned to the workshop group were also required to examine a resident's sleep data and in consultation with other members of the group, select an appropriate intervention to address any problems. Results showed that the workshop provided little 'added value'. However the individual's under the care of both groups of staff members displayed a significant increase in sleep efficiency and concurrent significant decreases in their sleep onset following intervention.

In an earlier study, Hylkema and Vlaskamp (2009) used a multiple base-line design to evaluate the impact of staff-administered, non-pharmacological sleep interventions on the sleep of individuals with intellectual disabilities living in residential settings. Interventions were designed by the researchers, and then relayed to the facility's own multidisciplinary teams, who were then responsible for implementing the advised treatment plans. Possible intervention strategies included increased activity during the day, sleep scheduling and changes to daily routines in order to promote sleep hygiene. Data from actigraphs revealed that, overall, 80.5% of participants showed improvements in sleep efficiency and sleep latency following the implementation of one or more of these intervention strategies. However, these findings are less promising when the results of child and adolescent participants are viewed in isolation. For instance, among the participants under the age of 20 (ranging from 8-19 years old), positive treatment effects were observed in only four out of the eight cases. Following further examination, researchers discovered that in two of the four cases with no positive treatment effect, the agreed intervention had not been implemented. No explanation was provided for the lack of treatment effect observed in the other two cases. The utility of this particular study is also limited by the fact that it did not report follow up data, nor the social validity (i.e. staff members acceptance and satisfaction with intervention procedures).

These initial studies suggest that staff-training programmes delivered in group-format, followed by the implementation of behavioural interventions, can improve the sleep quality of individuals with developmental disabilities living in care. However there is currently very little research conducted with children and adolescent samples, and the research that has been conducted with this population has produced mixed results (Hylkema & Vlaskamp, 2009). Therefore, more research into both the effectiveness and social validity of this treatment approach among youth with developmental disabilities is needed.

Rationale

This literature review has demonstrated the range of behavioural interventions currently used to treat sleep problems in children and adolescents with developmental disabilities. Antecedent based strategies have shown efficacy in treating sleep problems among this population. For example, studies have shown interventions that incorporate sleep hygiene to improve the sleep quality of children with developmental disabilities (Jan et al., 2008; Singh & Zimmerman, 2015; Vriend et al., 2011). The use of faded bedtime with and without response cost has shown particular success in the treatment of sleep problems with a circadian component, such as sleep onset delay and early morning waking (DeLeon et al., 2004; Delmere & Dounavi, 2017; Cuomo et al., 2017; Sanberg et al., 2018; Vriend et al., 2011). Lastly, visual supports such as Groclocks and social stories complement these more comprehensive strategies, and help the child understand and follow the intervention (Gray, 1998; Karkhaneh et al., 2010; Malow et al., 2014; McLay et al., 2019; Moore, 2004). Alternatively, consequence-based strategies, such as extinction procedures and use of rewards, have received significant empirical support (Etherton et al., 2016; Montgomery et al., 2004; Vriend et al., 2011; Weikshop et al., 2005). Studies have also found parent training to be a useful tool in the treatment of sleep problems, either as the sole intervention

component, or in combination with additional intervention support (Austin et al., 2013; Moss et al., 2014; Reed et al., 2009; Schlarb et al., 2011; Wade et al., 2007).

Research investigating both behavioural interventions and training programmes for the treatment of sleep problems has focused mainly on parent-administered interventions designed to treat sleep problems in children with developmental disabilities who live at home. This focus represents a significant limitation to existing literature. This review highlights the fact that not all youth with developmental disabilities are able to be cared for at home, and are instead cared for by staff at residential facilities (Friedman & Kalichman, 2014; Braddock et al., 2001; Ministry of Health, 2017). At present, this particular population of children has been largely omitted from literature. It cannot be assumed that children who are cared for outside the family home do not continue to experience the challenges associated with developmental disabilities, such as disturbed sleep. Given that sleep problems are disproportionately prevalent in children with developmental disabilities, and can have a number of associated negative consequences on child wellbeing, the exploration of staff-administered interventions implemented within residential settings is of considerable importance.

Recent research shows promise for the use of staff-training programmes to enhance social and communication skills, and reduce challenging behaviours among children and adolescents with developmental disabilities living in residential care (Ingersoll, Berger, Carlsen & Hamlin, 2017; Kossyvakis, Jones & Guldberg, 2016; Weinkauff, Zeug, Anderson, Ala'i-Rosales, 2011). However, this literature review yielded only two studies investigating a staff-focused approach for the treatment of sleep problems in this population. There is therefore a strong need for more research into the effectiveness of both staff training programmes and staff-delivered behavioural interventions to help treat sleep problems in the

children with developmental disabilities living in residential care.

This literature review also highlights the fact that, despite the availability of behavioural treatments for sleep problems, research indicates that a large proportion of families do not access them (Didden et al., 2002; Richdale & Robinson, 2004). Two key factors were identified in the literature that might contribute to this observation. First, it has been hypothesized that parents do not seek treatment for their child's sleep problems simply because a lack of knowledge in this area means that they fail to recognize them (McDowall et al., 2017; Owens et al., 2011; Robinson & Richdale, 2004; Shreck & Richdale, 2011). Secondly, studies have shown that parents of children with developmental disabilities commonly attribute behaviour problems, such as sleep disturbance, to factors that are internal, stable and outside the child's control (Hartley et al., 2008; Johnston & Freeman, 1997; Weiner 1980; Woolfson et al., 2011). Research associates these attributional biases with negative beliefs regarding the effectiveness of behavioural sleep interventions, which may also prevent parents from seeking treatment (Dardennes et al., 2006; Keenan et al., 2006; McDougall et al., 2005). Despite the suggestion that knowledge and attributions may represent barriers to treatment, studies are yet to evaluate these factors among staff members who care for the proportion of children with developmental disabilities who live in residential care. To ensure that treatment access among children residing in residential care, it is also important that these factors are assessed.

The current study builds on existing research about behavioural interventions to treat sleep problems in children with developmental disabilities, by evaluating the effectiveness of a staff-focused intervention approach. This overall objective will be achieved through two different, but related foci. First, this thesis records the sleep knowledge and attributions held by staff members working at a residential care facility for youth, and examines whether these

factors can be altered via participating in an educational, training workshop. As these factors may represent a possible barrier to treatment, it is important that their malleability be assessed. Therefore the first part of this study (Study One) is designed with the following four research questions:

1. What knowledge do staff members working at a residential facility for youth have about sleep problems in children with developmental disabilities?
2. Can staff members' knowledge of sleep problems be increased by an educational workshop?
3. What attributions do staff members make about sleep problems in this population, including their locus, stability, and controllability?
4. Are staff attributions about sleep problems altered following the provision of an educational workshop?

The second focus of this study follows on from the training provided in Study One, and is to evaluate the effectiveness of staff-delivered, individualized behavioural sleep interventions. This will be achieved by observing the impact of FBA-informed, behavioural sleep intervention plans, delivered by staff members, on the sleep behaviour of three children in their care. Therefore, Study Two is designed to answer the following research question:

1. Are staff-delivered, FBA informed, behavioural interventions effective in treating sleep problems in children with developmental disabilities and sleep problems who live in residential care?

This thesis consists of two studies: Study One will evaluate the impact of an educational workshop on staff members' knowledge and attributions about sleep problems in children with developmental disabilities. Study Two will use a multiple-baseline design to assess whether staff-delivered, behavioural interventions are effective in treating sleep problems experienced by children with developmental disabilities living in residential care. The information outlined in this chapter is common to both studies.

Sleep Research Team

The two studies included in this thesis were conducted as part of a wider research project undertaken by a team of researchers at the University of Canterbury (UC). The research team consists of senior academics, registered psychologists, registered intern psychologists, as well as PhD and Masters students. The purpose of the larger project is to evaluate the effectiveness of parent-implemented function-based interventions for sleep problems in children with developmental disabilities.

Ethics

The current study received ethics approval from the University of Canterbury Ethics Committee (HEC 2018/48).

Setting

The study took place at a facility in Australasia that provides residential care for individuals with developmental disabilities. The facility comprises a number of individual houses, each of which accommodates up to six children and adolescents (between seven – 21 years of age). Each house has an assigned 'house parent', also known as a 'house manager'. The role of the house manager is to oversee the running of the house and provide a 'parental'

presence for the children and adolescents in their care. To ensure that they are available at all times, the house managers live in accommodation attached to each house. In addition to the house manager, residents are assisted by a range of support staff, trained in providing care for those with developmental disabilities. For the remainder of this thesis support staff will be referred to as ‘staff members’. Staff members at the facility work in shifts, meaning that there are day staff members and night staff. Night staff members are those who supervise the children at night. Staff members who work in the day support residents with their morning and evening routines. In between these times the children and adolescents attend an on-site school and are cared for by school staff members. At 9.00pm, the night staff commence their shift and the day staff go home. At least one staff member is present and awake in each house throughout the night. At 7.00am the day staff return to relieve night staff.

Recruitment and Consent

The residential care facility approached the research team at the UC Pukemanu Centre, requesting staff training and support to manage the sleep disturbance observed in a number of residents. Following initial contact and remote discussions, a lead member of the UC research team met with the director of the facility (the residential manager) and house managers in person to discuss the project and to observe the setting in which the intervention would take place. During this meeting, the researcher discussed what would be required from the facility and its staff members, the type of support that the research team could provide and the topic of confidentiality.

The residential manager then shared the information discussed at this initial meeting with the facility’s Board of Trustees. An information sheet written by a lead member of the research team was also provided. Once all parties had agreed to participate in the study, consent was obtained. Formal written consent was first obtained from the Board of Trustees,

the director of the facility, and the residential house managers for the houses that were later involved in this project. Upon identifying potential participants in this project, information about the study was then shared with the parents and staff members who would be involved. The information provided included: (a) Background and previous experience of researchers involved; (b) the aims of the current study; (c) possible treatment strategies that might be employed; (d) approximate study timeline; (e) a guarantee that confidentiality of participants would be maintained subject to the usual limits; and (f) details about what would be required from parents and staff members (both specific tasks and approximate time commitment). Following these discussions, written consent was obtained from the parents of each of the participants and all other staff members who worked at the facility and would be involved in the study. A copy of all information sheets and consent forms is provided in Appendices A to G.

Participant Anonymity and Confidentiality

In order to protect the anonymity of the facility and all participants involved in the current study, the description of the setting and participants involved in this research is purposefully vague. For example, the name and specific location of the facility is omitted, limited information is provided about the staff and child participants; the latter have also been assigned pseudonyms in order to keep their identity confidential.

Chapter 3

Study One Method

Study Design

The core approach of this study was pre-post assessment of change, with replication across cases (participants), and across dependent variables (staff members knowledge of sleep problems and attributions regarding their locus of causality, stability and controllability).

Participants

Recruitment. As the facility approached the Pukemanu Centre at UC requesting staff training and support, no participant recruitment was required.

Inclusion criteria. Staff members were eligible to participate in the study if they were willing to: (a) Attend both staff-training workshops; (b) participate in the treatment process and support the gathering of data; and (c) implement the recommended intervention.

Participant characteristics. Participants consisted of 24 staff members working at a residential care facility in Australasia. All participants were adults of working age. Of the participants, three were residential house managers, and the remaining 21 participants were support staff members. The amount of time that staff members had worked at the facility ranged from less than six months to over five years. All staff members included in this study had children in their care with some form of sleep disturbance.

Dependent Variables and Measures

Staff members' knowledge of sleep problems in children with developmental disabilities. Staff members' level of knowledge regarding sleep in children with developmental disabilities was assessed before and after the educational workshop. This was measured using a *Staff Sleep Knowledge Questionnaire* that was developed by the research team. The questionnaire included 17 multiple-choice items, which related to the content delivered during the workshop. The questions were designed to assess staff members' knowledge of healthy sleep patterns in children and adolescents, the types of sleep problems experienced by those with developmental disabilities, causes of sleep problems in children and adolescents with developmental disabilities, and strategies used to assess and treat sleep problems. A copy of the *Staff Sleep Knowledge Questionnaire* is provided in Appendix H. Change in staff members' sleep knowledge as a result of the training was measured via the comparison of the number of correct responses prior to the workshop to the number of correct responses after the workshop.

Staff members' attributions about sleep problems in children with developmental disabilities. Staff attributions regarding sleep problems in children with developmental disabilities were assessed using a *Staff Attribution Questionnaire*, which was created by the researchers. The questionnaire was designed to assess staff members' attributions regarding the locus, stability and controllability of sleep problems. Staff members were presented with four short vignettes, each describing a specific child with developmental disabilities (ASD) and type of sleep problem. Each scenario was designed to reflect different underlying causes and behavioural manifestations of sleep problems in order to assess whether staff attributions and beliefs differed, depending on the presenting problem and child characteristics. Vignette one described a boy displaying bedtime resistance; vignette two described a girl who was experiencing sleep onset delay and night waking; vignette three referred to a boy who displayed sleep-interfering stereotypy; and vignette four described a

girl who was experiencing sleep-interfering anxiety. For each vignette, staff members were asked to indicate on a 5-point Likert Scale, the extent to which they agreed with the following five statements: *The sleep problem is likely to resolve without treatment; is part of the child's natural sleep cycle; is part of the child's ASD; is learnt and can be changed; and if parents change their responses the behaviour will change.* The options included in the scale were as follows: strongly disagree, disagree, somewhat agree, agree, and strongly agree. A copy of the *Staff Attribution Questionnaire* is provided in Appendix I.

In order to assess whether staff members' attributions about sleep problems in children with developmental disabilities changed as a result of training, the questionnaire was completed pre- and post-participation in the workshop. Any alteration in staff members' attributions about sleep problems was measured by the change in their responses across the two time points.

Procedure

Study one consisted of three phases: (a) assessment of staff members baseline knowledge and attributions about sleep problems in children and adolescents with developmental disabilities; (b) participation in a two hour training workshop; (c) assessment of staff members post training knowledge and attributions of sleep problems in children and adolescents with developmental disabilities.

Assessment of baseline knowledge and attributions. Prior to participating in the workshop, staff members were asked to complete one questionnaire that focused on their knowledge of sleep problems in youth with developmental disabilities (see *Staff Sleep Knowledge Questionnaire*), and one that explored their attributions about the locus, stability and controllability of sleep problems in this population (see *Staff Sleep Attribution*

Questionnaire). These questionnaires were provided in person by the researcher and took approximately 10 minutes per questionnaire to complete.

Staff Training workshop. Researchers from the UC Sleep Research Team visited the residential care facility to provide staff members with a two-hour educational training workshop (described in greater detail below). Workshops were provided on-site at the residential care facility. Two identical workshops were presented to enable the participation of both day staff members and night staff. The workshop presented to the day staff members was presented at midday, while the residents were at school; the second session for night staff members was held in the late evening, before they began their shift.

Workshop content. The purpose of the workshop was to increase staff members' level of knowledge related to sleep problems in children and adolescent's with developmental disabilities. A registered intern psychologist and the researcher (a Masters' research thesis student) delivered the workshop via PowerPoint, which took approximately two hours. The content of the workshop focused on: the prevalence and type of sleep problems commonly experienced by children and adolescents with developmental disabilities; the aetiology of sleep problems in children with developmental disabilities, including the role of biopsychosocial and behavioural factors; the secondary impact of sleep problems on children's daytime functioning and well-being; the FBA of sleep problems, including common antecedent and consequence variables that impact upon children's sleep; and empirically-supported, behaviourally-based sleep interventions for children with developmental disabilities (e.g. sleep hygiene modifications, modification to bedtime routines and sleep/wake schedules). At the end of the PowerPoint presentation, staff members were presented with three case vignettes, each describing a scenario in which a child was experiencing some sort of sleep disturbance. With the assistance of researchers, staff

members were then required to identify any antecedent or consequence factors that they thought might be maintaining the sleep problem, and suggest possible treatment strategies. Participants were then given the opportunity to ask questions.

Assessment of knowledge and attributions post-workshop. Immediately following the workshop, staff members were asked to complete the same *Knowledge Questionnaire* and *Attribution Questionnaire* to assess any resulting change in these variables.

Data Analysis

The questionnaire data were analysed for the direction and consistency of change. This was done on a case-by-case, and for the *Staff Attribution Questionnaire* data, on a vignette-by-vignette basis using modified Brinley plots. Modified Brinley plots are scatterplots that compare individual scores over two time points (e.g. pre-workshop and post-workshop) (Blampied, 2017), and were used to identify the effects of the training workshop on staff members' responses. At a group aggregate level, two effect sizes were calculated: Cohen's d effect size (Cohen, 1988; Lakens, 2013) with 95% confidence intervals (95% CI) and the Common Language ES (CLES). Positive values of d indicate change in the desirable direction if it is anticipated that the workshop should increase scores on a particular measure. Alternatively, negative d values indicate change in the desirable direction if the workshop should decrease scores on a particular measure. As suggested by Cohen (1988) effect sizes for this thesis will be interpreted as follows: small ($d=0.2$), medium ($d=0.5$), and large ($d=0.8$). The CLES (Lakens, 2013; McGaw & Wong, 1992) is the probability that a randomly selected score from one set of data will be greater than a randomly selected score from another set of data. This probability is expressed as a percentage.

Chapter 4

Study One Results

The following section presents the data on staff members' knowledge and attributions about sleep problems prior to, and following the workshop. The chapter will begin by presenting the data from the *Staff Knowledge Questionnaire*, followed by data pertaining to the *Staff Attribution Questionnaires*. Participants' responses to these items are presented as modified Brinley plots showing change from pre-to post-intervention.

The Interpretation of Modified Brinley Plots

Modified Brinley plots display individual change over time. As shown in Figure 1, pre-intervention scores are plotted on the X-axis, and post-intervention scores are plotted on the Y-axis. This means that each individual data set is displayed as a co-ordinate pair on a scatterplot. Assuming that the X and Y axis have the same origin of scale, if there is no change between scores at time 1 (in this case pre-workshop) and time 2 (post-workshop), then the all data points will lie on the 45° line, as shown in the top left diagram in Figure 1 (Blampied, 2017). Alternatively, systematic movement of the co-ordinate pairs either below or above the 45° line indicates either an increase or decrease in scores for some or all participants (Blampied, 2017). Therefore, when interpreting the data from the *Staff Knowledge Questionnaire*, data points that move above the 45°line indicate an increase in knowledge about sleep problems, while those that move below the 45° line suggest a decrease in knowledge. Alternatively, when interpreting the modified Brinley plots displaying the data from the *Staff Attribution Questionnaires*, data points that move above the 45°line indicate an increase in level of agreement, while those that move below the 45° line suggest a decrease in agreement.

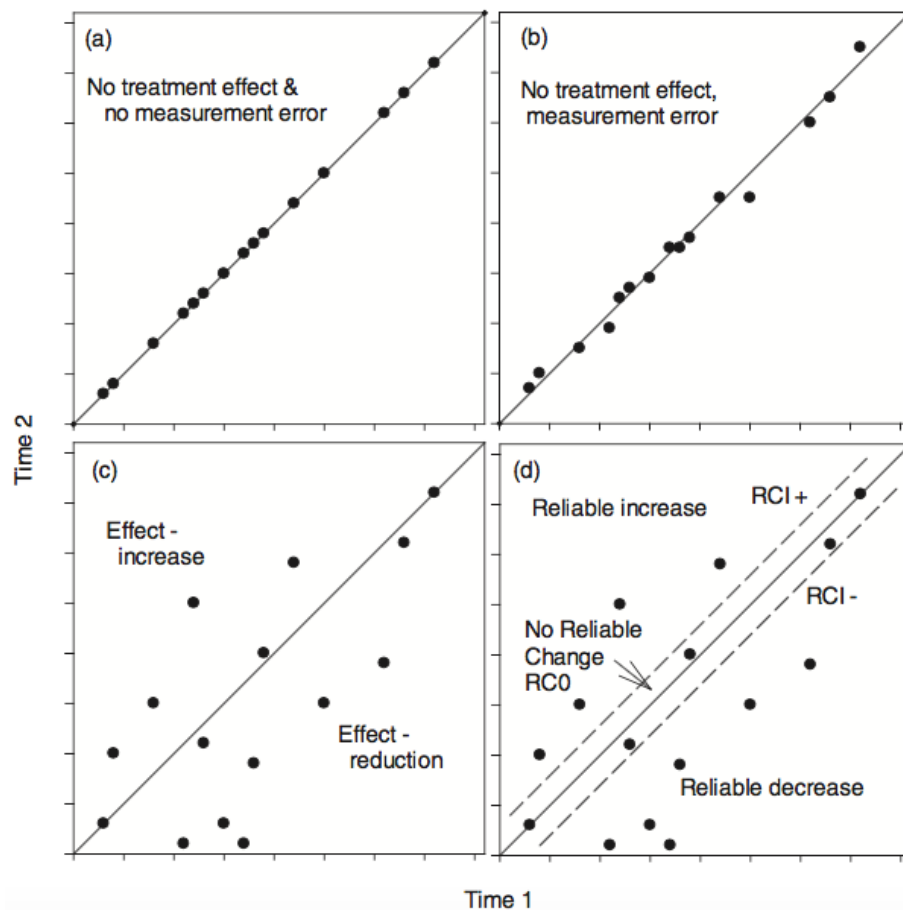


Figure 1. Interpretation of modified Brinley plots when there is no change (top left right) and when there is treatment effect (bottom left right) (Blampied, 2017).

Staff Knowledge Questionnaire

To compare staff members' level of knowledge pre and post-workshop, the mean number of questions answered correctly was calculated and compared across these two time points. It was hypothesized that staff members would have a greater knowledge of sleep problems after participating in the workshop. It was therefore expected that scores would be higher at Time 2 (post-workshop) compared to time 1 (pre-workshop), and the data points would lie above the 45° on the modified Brinley plots. Data from the *Staff Knowledge Questionnaire* is presented in Figure 2. A total of 24 staff members completed the questionnaire. The analysis showed that the average number of questions that staff members answered correctly was significantly lower before participating in the workshop ($M = 8.9$, $SD = 3.15$) when compared to post-workshop ($M = 14$, $SD = 2.73$). The effect size for this

analysis ($d = 1.71$) exceeded Cohen's (1988) convention for a large effect ($d = .80$) with the lower limit of the 95% CI [0.68, 1.73] indicating at least a medium effect size (i.e., greater than .5). As shown in Figure 2., the increase in knowledge was consistent across staff members, with 22 of the 24 staff answering more items correctly following the workshop than they did prior. The remaining two staff members answered the same number of questions correctly pre- and post-participation in the workshop, with one staff member answering seven questions correctly, and the other answering 13 correctly at both time points. As neither of these data points are at the maximum score, the possibility that this observation was caused by a ceiling effect can be ruled out. The Common Language Effect Size (CLES) indicates that the likelihood of a staff member scoring higher at Time 2 (post-workshop) than at Time 1 (pre-workshop) is 94%.

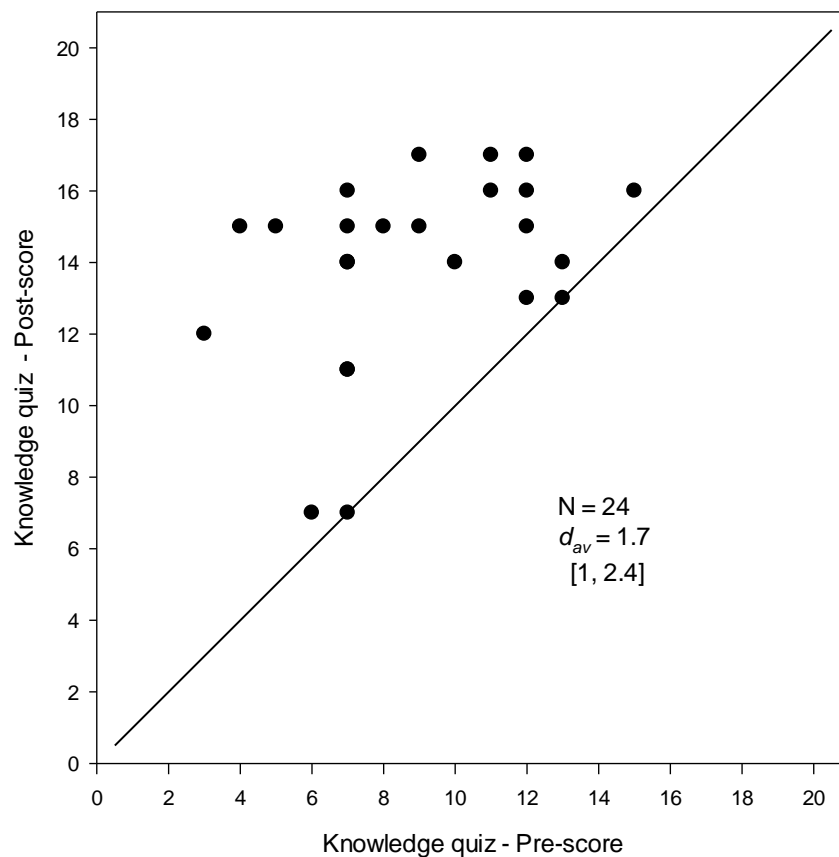


Figure 2. Modified Brinley plot showing change in scores on *Staff Knowledge Questionnaire* pre- to post-workshop.

Staff Attribution Questionnaire

The *Staff Member Attribution Questionnaire* was completed by 22 out of the 24 staff members both prior to, and after the workshop. Two post-workshop questionnaires were returned incomplete and were therefore not able to be analyzed. To analyze the data from these questionnaires, staff member responses were coded as follows: *strongly disagree* = 1, *disagree* = 2, *somewhat agree* = 3, *agree* = 4 and *strongly agree* = 5. Thus, higher scores indicate higher level of agreement with each item. Pre-workshop responses were compared to post-workshop responses to evaluate the effect of training on staff attributions about sleep problems. The data from this analysis are presented in Figures 3-6. The following section will describe staff members' responses to the five items across each of the four vignettes. Any re-occurring patterns or important differences between items/vignettes will also be noted.

For the remainder of this chapter, Item 1 will refer to the statement "*it is likely to resolve without treatment*"; Item 2 refers to the statement "*it is part of the child's natural sleep cycle*", Item 3 is the statement "*this behaviour is part of the child's ASD*", Item 4 refers to "*this behaviour is learnt and can be changed*" and Item 5 refers to the statement "*if the parents change their responses the behaviour will change*". It was hypothesised that following the workshop, change in responses to Items 1-3 would be in the negative direction (i.e. staff members would agree more strongly with these items pre-workshop), while the direction of change in responses to Item 4 and Item 5 would be positive (i.e. staff members would agree more strongly with these items post-workshop). This hypothesis was made for all four vignettes.

Vignette one. The first vignette described a boy with ASD who displayed bedtime resistance. The data for this vignette is presented in Figure 3. The mean response to Item 1 (*sleep problem likely to resolve without treatment*) at Time 1 (pre-workshop) was higher ($M = 2.72$, $SD = 0.94$) than the mean response at Time 2 (post-workshop) ($M = 1.77$, $SD = 0.53$).

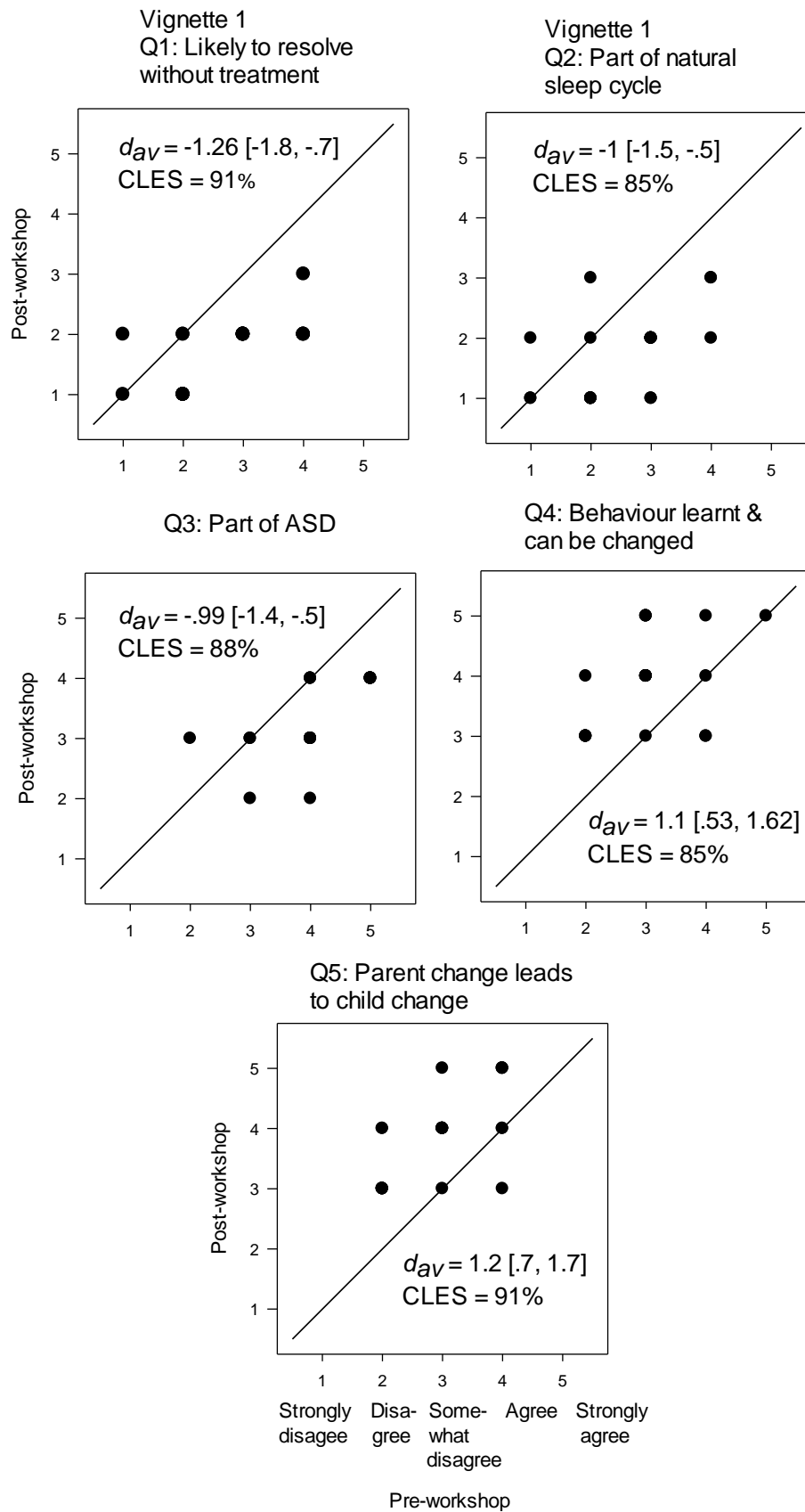


Figure 3. Modified Brinley plot showing change in staff responses to the *Staff Members Attribution Questionnaire* from pre- to post- workshop – Vignette 1.

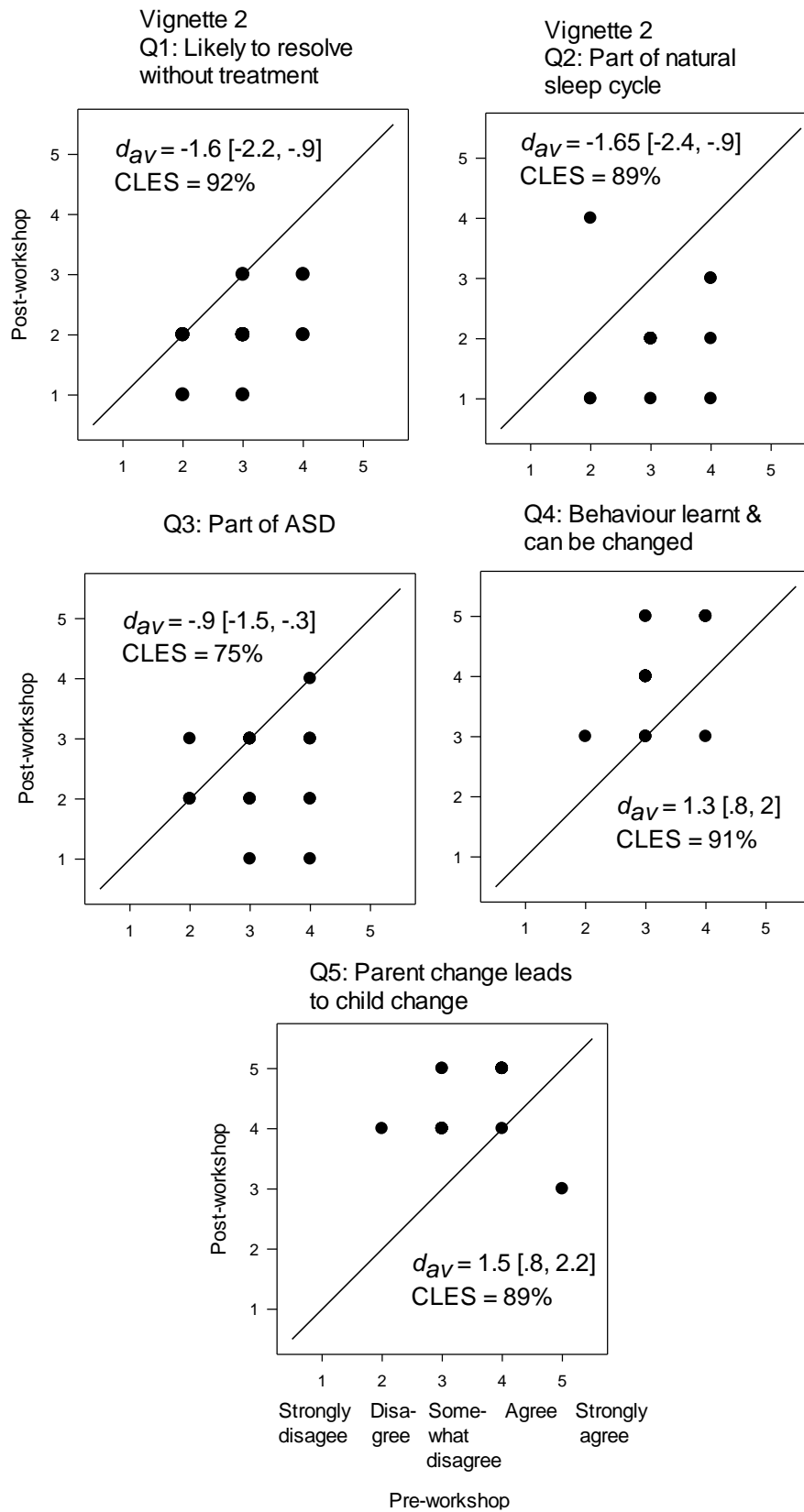


Figure 4. Modified Brinley plot showing change in staff responses to the *Staff Members Attribution Questionnaire* from pre- to post- workshop – Vignette 2.

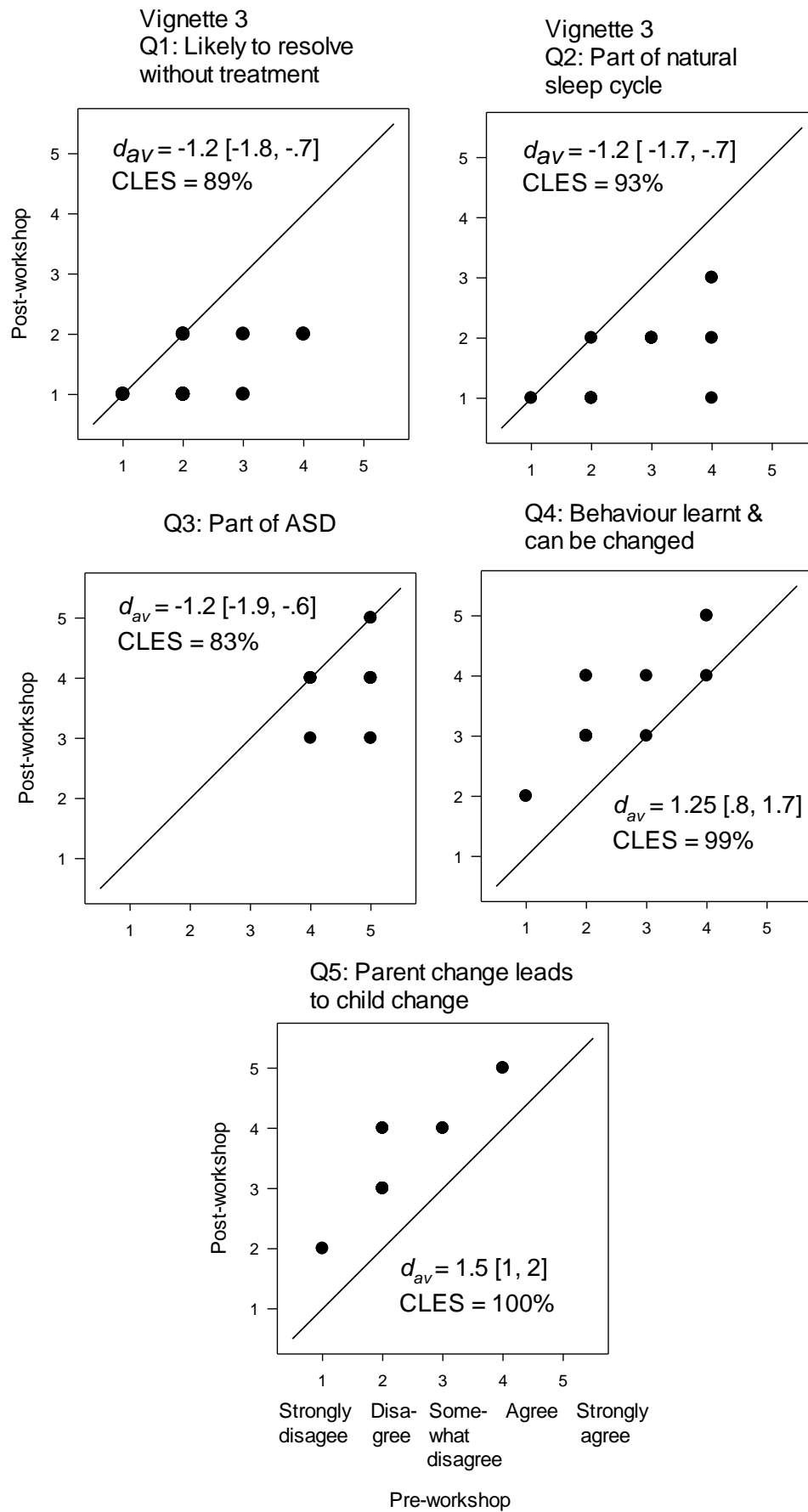


Figure 5. Modified Brinley plot showing change in staff responses to the *Staff Attribution Questionnaire* from pre- to post- workshop – Vignette 3

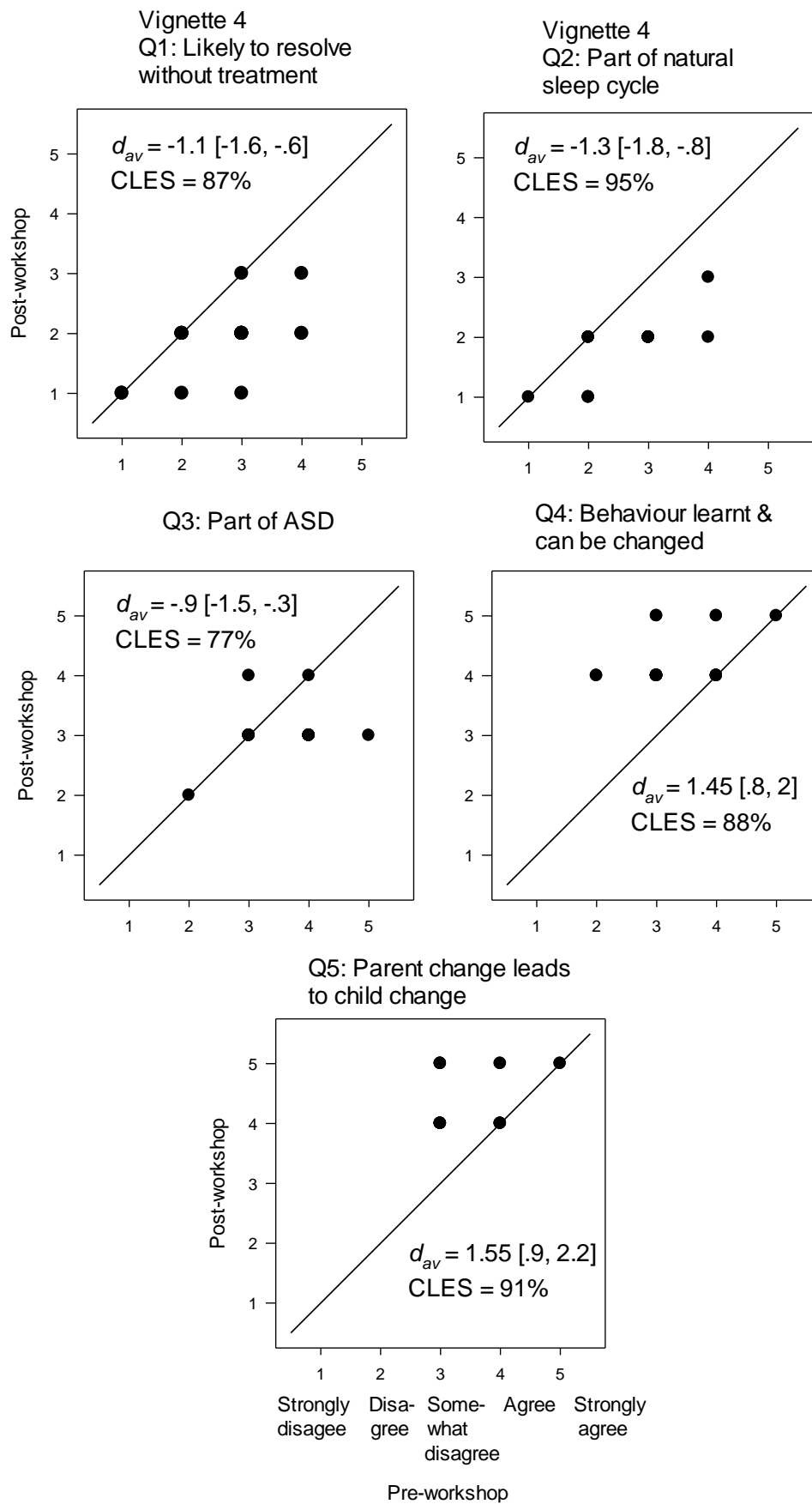


Figure 6. Modified Brinley plot showing change in staff members' responses to the *Staff Members Attribution Questionnaire (Two)* from pre- to post- workshop – Vignette 4

The effect size (ES) for this change was large ($d=-1.26$), 95% CI $[-1.80, -.70]$, with a Common Language Effect Size (CLES) of 91%. This indicates that after controlling for individual differences, the likelihood that a staff member scored higher (i.e. agreed more strongly with this item) at Time 1 than Time 2 is 91%. At Time 1, the distribution of responses to Item 1 ranged from '*strongly disagree*' ($n = 2$) to '*agree*' ($n = 4$). The most common response ($n=8$,) was in the middle at '*somewhat agree*'. As shown in Figure 3, 18 staff members reported a decrease in level of agreement with Item 1 following the workshop. Three staff members showed no change, and one staff member's level of agreement increased post-workshop. Following the workshop, the distribution of scores ranged from '*strongly disagree*' ($n = 6$) to '*somewhat agree*' ($n = 1$), with the majority ($n=15$) indicating that they now '*disagreed*' with the statement. Thus, the overall direction of change was relatively consistent across staff members, in that the majority thought the sleep problem was less likely to resolve without treatment post-workshop.

The mean response to Item 2 (*the sleep problem is part of the natural sleep cycle*) was higher at Time 1 ($M = 2.5$, $SD = 0.91$) than at Time 2 ($M = 1.68$, $SD = 0.72$). The ES for this change was large ($d=-1.0$), 95% CI $[-1.5, -0.49]$, with a CLES of 85%. Before the workshop, responses ranged between *strongly disagree* ($n = 3$) to *agree* ($n=3$), with staff members most commonly reporting *disagree* and *somewhat agree* in response to this item ($n = 8$ for both). Following the workshop, responses ranged from *strongly disagree* ($n = 10$) to *somewhat agree* ($n = 3$) and the most common answer given was *strongly disagree* ($n=10$). Therefore, the dominant trend, displayed by 18 staff members, was a decrease in agreement with Item 2. Two staff members increased their level of agreement with this statement and the remaining one staff member did not change their response. This suggests that the majority of staff were less likely to believe that the sleep problem was part of the child's natural sleep cycle following the workshop.

Item 3 (*sleep problem is a part of the child's ASD*) followed the same pattern as the first two items. The mean response at Time 1 was higher ($M = 4.09$, $SD = 0.81$) than that mean response at Time 2 ($M = 3.36$, $SD = 0.66$). This equated to a CLES of 88% and a large ES ($d = -0.99$), 95% CI [-1.44, .051]. At Time 1, responses ranged from 'disagree' ($n = 1$) to 'strongly agree' ($n = 7$). The response most commonly given at this time point was 'agree' ($n = 11$). Figure 3 shows that following the workshop 16 staff members reported a change in the negative direction (i.e. a decrease in agreement), one staff member indicated they agreed more strongly with the statement after participating in the workshop, and the responses of five individuals remained the same. At Time 2 the distribution of scores was slightly smaller, only ranging from 'disagree' ($n = 2$) to 'agree' ($n = 10$), with the most commonly reported responses being 'somewhat agree' ($n=10$) and 'agree' ($n=10$). This indicates that the dominant trend was such that staff members were less likely to perceive the sleep problem to be part of the child's ASD post-workshop.

For Item 4 (*the behaviour is learnt and can be changed*) and Item 5 (*parent change leads to change in behaviour*), the overall change in staff member responses went in the opposite direction. The mean staff member response to Item 4 was lower at Time 1 ($M = 3$, $SD = 0.82$) than Time 2 ($M = 3.86$, $SD = 0.77$), with a large ES ($d=1.09$), 95% CI [0.53, 1.62] and CLES of 88%. This CLES indicates that the probability of a staff member's response being higher (i.e. reporting a stronger level of agreement) at Time 2 than Time 1 was 88%. Prior to the workshop, responses to this item ranged between 'disagree' ($n=6$) to 'strongly agree' ($n=1$). The most common response pre-workshop was 'somewhat agree' ($n=11$). Following participation in the workshop, scores were distributed closer towards the higher end of the scale, ranging between 'somewhat agree' ($n=8$) and 'strongly agree' ($n=5$), with most staff members responding with 'agree' ($n=9$). Thus, the dominant trend was a decrease in agreement with Item 4. This was true for 18 staff members, while two staff members

reported a decrease in level of agreement with this item following the workshop, and two staff members' responses remained the same. This result suggests that following the workshop staff were more likely to think that the sleep problem was learnt and could be changed.

The mean response to Item 5 was also lower at Time 1 ($M = 2.95$, $SD = 0.79$) compared to Time 2 ($M = 3.86$, $SD = 0.71$). This change produced a large ES ($d = 1.21$), 95% CI [0.68, 1.73], with a CLES of 91%. At Time 1, the most common response given by staff members was 'somewhat agree' ($n=9$), with the remaining responses distributed between 'disagree' ($n=7$) and 'agree' ($n=6$). At Time 2, this distribution had shifted, ranging between 'somewhat agree' ($n=7$) to 'strongly agree' ($n=4$). The most common response given at this time-point was 'agree' ($n=11$). As shown in Figure 3, the change in response was relatively consistent, with 18 staff members indicating that they agreed more strongly with Item 5 after participating in the workshop. Three staff members did not change their responses, and one staff member's level of agreement decreased. Thus, staff tended to believe that the sleep problem was more likely to change if parent behaviours changed after the workshop compared to before the workshop.

Vignette two. Vignette two provided a brief description of a girl with ASD who experienced sleep onset delay. The change in staff member responses between pre- and post-workshop (presented in Figure 4) followed a similar pattern to those observed in vignette one. The mean response to Item 1 (*sleep problem likely to resolve without treatment*) was higher at Time 1 ($M = 2.82$, $SD = 0.59$) than Time 2 ($M = 2.0$, $SD = 0.44$). This comparison produced a large ES ($d = -1.58$), 95% CI [-2.24, -0.9] and a CLES of 92%. The distribution of responses pre-workshop ranged between 'disagree' ($n=6$) and 'agree' ($n=2$), with the most common response being in the middle with 'somewhat agree' ($n=14$). Following the workshop, the distribution of responses shifted and become more clustered. At Time 2, the

most frequent response to Item 1 was '*disagree*' (n=18), with the remaining responses split evenly between '*strongly disagree*' (n=2) and '*somewhat agree*' (n=2). This indicates that overall, staff members' level of agreement with Item 1 decreased following the workshop. This change was observed in 17 staff members, while the remaining five staff members showed no change following the workshop. Thus, the overall direction of change was relatively consistent across staff members, in that the majority thought the sleep problem was less likely to resolve without treatment post-workshop.

The mean response to Item 2 (*the sleep problem is part of the natural sleep cycle*) was also greater at Time 1 ($M = 3.05$, $SD = 0.58$) than Time 2 ($M = 2.0$, $SD = 0.69$), with a large ES ($d = -1.65$), 95% CI, [-2.38, -0.89], and a CLES of 98%. At Time 1, responses ranged from '*disagree*' (n=3) to '*agree*' (n=15), with the top of this range also representing the most common response. Following the workshop, the most frequently given response changed to '*disagree*' (n=15), and the range increased to between *strongly disagree* (n=4) and *agree* (n=1). This decrease in agreement with Item 2 was consistent across staff members, with 21 of the 22 participants reporting a change in this direction. Thus, the direction of change was consistent across staff, in that the majority were less likely to believe that the sleep problem was part of the child's natural sleep cycle following the workshop.

The mean response to Item 3 (*sleep problem is a part of the child's ASD*) was greater at Time 1 ($M = 3.14$, $SD = 0.71$) compared to Time 2 ($M = 2.5$, $SD, 0.74$). However, both the ES ($d = -0.88$), 95 CI [-1.48, -0.26], and CLES (75%) for this comparison were smaller relative to previous items. Prior to the workshop, responses ranged from '*disagree*' (n=4) to '*strongly agree*' (7), with '*somewhat agree*' being the most common response (n=11). Following the workshop, the distribution of responses spread slightly, to range from '*strongly disagree*' (n=2) to '*strongly agree*' (n=1). The mode however did not change, with '*somewhat agree*' remaining the most common response (n=11). As shown in Figure 4, 10

staff members' level of agreement with this item decreased post-workshop, 10 staff members did not change their response, and two reported an increase in agreement. This indicates that the direction of change for this item was less consistent, with just below half of the staff members reporting that they thought the sleep problem was less likely to be part of the child's ASD diagnosis following the workshop.

As with vignette one, the change in staff members' responses to Item 4 (the *behaviour is learnt and can be changed*) and Item 5 (*parent change leads to change in behaviour*) went in the opposite direction to that observed for Items 1, 2 and 3. For Item 4, the mean response at Time 1 ($M = 3.18$, $SD = 0.50$) was lower than that at Time 2 ($M = 4.05$, $SD = 0.72$), ($d = 1.39$), 95% CI [0.78, 1.98]. The CLES for this item was high, at 91%. Prior to the workshop, responses ranged from 'disagree' ($n=1$) to 'agree' ($n=5$), and the most common response was 'somewhat agree' ($n=16$). Following the workshop, responses were distributed between 'somewhat agree' ($n=5$) and 'strongly agree' ($n=6$), while the most common response at this time-point was 'agree' ($n=11$). The change in distribution suggests that on average, staff members' level of agreement with this item increased following participation in the workshop. This was observed in 18 staff members, while three did not change their response, and one reported a decrease in agreement. This suggests that the majority of staff thought the sleep problem was more likely to be learnt and therefore able to be changed post-workshop.

The mean response to Item 5 was also lower at Time 1 ($M = 3.46$, $SD = 0.94$) than Time 2 ($M = 4.41$, $SD = 0.59$). This comparison produced a large ES ($d = 1.51$), 95% CI [0.81, 2.19], and CLES of 89%. At Time 1, responses ranged between 'disagree' ($n=1$) and 'strongly agree' ($n=1$). However the majority of responses were clustered around 'agree' ($n=9$) and 'somewhat agree' ($n=11$). Out of the 22 staff members who completed the questionnaire, 20 reported that their level of agreement with this item increased following the workshop, one staff member reported a decrease in agreement, and one staff member's

response remained the same. As a result, the post-workshop distribution was more strongly skewed toward higher scores (i.e. higher level of agreement), with responses at Time 2 ranging from ‘*somewhat agree*’ (n=1) to ‘*strongly agree*’ (n=10), while the most common response at this time point was ‘*agree*’ (n=11). Thus, overall, staff members were more likely to believe that the sleep problem would change if parent behaviours changed after the workshop compared to before the workshop.

Vignette three. Vignette three provided staff members with a description of a boy with ASD who was engaging in sleep-interfering stereotypic behaviours. The data for vignette three is displayed in Figure 5. For Item 1 (*sleep problem likely to resolve without treatment*), the mean response by staff members at Time 1 ($M = 2.68$, $SD = 0.94$) was greater than the mean response at Time 2 ($M = 1.91$, $SD = 0.53$), ($d = -1.24$), 95% CI [-12.24, -0.9]. The CLES for this comparison was 87%. Pre-workshop, the distribution of responses ranged from ‘*strongly disagree*’ (n=4) to ‘*agree*’ (n=2), with the most common response being ‘*disagree*’ (n=14). Following the workshop, the distribution became less spread, with the majority of staff members responding with ‘*strongly disagree*’ (n=16) and the remaining responses being ‘*disagree*’ (n=6). This was due to 16 staff members reporting a decrease in agreement with Item 1 following participation in the workshop, while six staff members did not change their response. Thus, the majority staff members thought the sleep problem was less likely to resolve without treatment post-workshop.

Responses to Item 2 (*the sleep problem is part of the natural sleep cycle*) followed a similar pattern, with the mean response found to be higher pre-workshop ($M = 2.64$, $SD = 0.73$) compared to post-workshop ($M = 1.82$, $SD = 0.50$), ($d = -1.19$), 95% CI [-1.68, -0.69]. The CLES for this item was high, at 93%. At Time 1, the distribution of responses was evenly spread, ranging from ‘*strongly disagree*’ (n=2) to agree (n=6) with the most common responses being both ‘*disagree*’ (n=7) and ‘*somewhat agree*’ (n=7). At Time 2, responses

ranged from ‘*strongly disagree*’ (n=8) to ‘*somewhat agree*’ (n=3). The response most frequently given at this time-point was ‘*disagree*’ (n=11). This change in distribution suggests that there was an overall decrease in agreement with Item 2. This was observed in 18 staff members, while four responses remained the same. Therefore, staff were less likely to believe that the sleep problem was part of the child’s natural sleep pattern after participating in the workshop.

Staff responses to Item 3 (*sleep problem is a part of the child’s ASD*) were also higher at Time 1 ($M = 4.64$, $SD = 0.49$) than Time 2 ($M = 4.0$, $SD = 0.95$). The ES for this change was large to medium ($d = -1.24$) at 95% CI [-1.88, -0.58], and produced a CLES of 83%. Prior to the workshop, responses were highly clustered, with the only two responses given being ‘*agree*’ (n=8) and ‘*strongly agree*’ (n=14). While 12 staff members did report a decrease in agreement post-workshop, 10 staff members reported no change. This indicates that just over half of staff indicated that they were less likely to attribute the sleep problem to the child’s ASD diagnosis following the workshop. This produced a post-workshop distribution that ranged from ‘*somewhat agree*’ (n=3) to ‘*strongly agree*’ (n=3), with the most common response being ‘*agree*’ (n=16). Thus, despite the moderate to large ES calculations, the change in responses to Item 3 was less significant compared to that observed for Item 1 and Item 2.

The direction of change observed in staff members’ responses to Item 4 and Item 5 was again in the opposite direction compared to Items 1 to 3. The mean response to Item 4 (*the sleep problem is learned and can be changed*) was lower ($M = 2.27$, $SD = 0.83$) before participating in the workshop, compared to after ($M = 3.27$, $SD = 0.77$), with a large effect size ($d = 1.25$), 95% CI [0.81, 1.69] and a very high CLES of 99%. The high CLES is reflected in the individual change in responses, with 20 staff members reporting an increase in agreement with Item 4 following the workshop. The remaining two staff members did not

change their response. Prior to the workshop, responses ranged from ‘*strongly disagree*’ (n=2) to ‘*agree*’ (n=3), with the most common response being ‘*disagree*’ (n=15). Following the workshop, responses ranged from ‘*disagree*’ (n=2) to ‘*strongly agree*’ (n=2). The most common response at Time 2 was ‘*somewhat agree*’ (n=14). Thus, there was a strong trend of increasing agreement for Item 4. This suggests that the majority of staff were more likely to believe that the sleep problem was learned and therefore able to be changed post-workshop.

The change in responses to Item 5 followed a similar pattern. The mean response observed at Time 1 ($M = 2.27$, $SD = 0.77$) was smaller than that observed at Time 2 ($M = 3.46$, $SD = 0.8$). The effect size for this item ($d = 1.51$), at 95% CI [1.01, 2] was the largest observed for Vignette Three, and the CLES (100%) was the highest for the entire questionnaire. Prior to the workshop, responses ranged from ‘*strongly disagree*’ (n=2) to ‘*agree*’ (n=2), with ‘*disagree*’ being the most common answer (n=14). As shown in Figure 5, all 22 staff members reported that they agreed more strongly with this statement following the workshop. This resulted in a post-workshop distribution that ranged between ‘*disagree*’ (n=2) and ‘*strongly agree*’ (n=2), while the most common answer at this time-point was ‘*somewhat agree*’ (n=10). Thus, the direction of change was highly consistent, with all staff members indicating that they were more likely to agree that the sleep problem would change if parent behaviours changed following participation in the workshop compared to beforehand.

Vignette four. The last vignette described a girl with ASD who experienced sleep-interfering anxiety and engaged in co-sleeping. The data for this vignette is shown in Figure 6. Staff responses followed the same pattern as the previous three vignettes. For Item 1 (*sleep problem likely to resolve without treatment*), the mean response was higher at Time 1 ($M = 2.68$, $SD = 0.84$) than at Time 2 ($M = 1.91$, $SD = 0.53$), with an effect size of ($d = -1.10$), 95% CI [-1.62, -0.57] and a CLES of 87%. At Time 1, responses ranged from ‘*strongly disagree*’

(n=2) to ‘agree’ (n=3). The most common response pre-workshop was ‘*somewhat agree*’ (n=11). At Time 2, the range of responses had decreased to between ‘*strongly disagree*’ (n=4) and ‘*somewhat agree*’ (n=2), and the most common response had become ‘*disagree*’ (n=16). This shift in distribution was caused by the decrease in agreement with Item 1 that was observed among 16 staff members. The remaining eight staff members did not change their response between pre- and post-workshop. This indicates that overall, staff thought that the sleep problem was less likely to resolve without treatment after the workshop.

The mean response to Item 2 (*the sleep problem is part of the natural sleep cycle*) was also higher at Time 1 ($M = 2.64$, $SD = 0.73$) than Time 2 ($M = 1.82$, $SD = 0.50$). This produced a large ES ($d = -1.31$), 95% CI $[-1.82, -0.79]$, and a high CLES of 95%. Prior to the workshop, responses to Item 2 ranged from ‘*strongly disagree*’ (n=1) to ‘*agree*’ (n=2), with the most common response being ‘*somewhat agree*’ (n=11). As shown in Figure 6., following the workshop, 17 staff members reported a decrease in agreement with this item, with the remaining five responses remaining the same. This resulted in a post-workshop distribution that ranged from ‘*strongly disagree*’ (n=5) to ‘*somewhat agree*’ (n=1). At Time 2, the most frequent response was ‘*disagree*’ (n=16). Thus, the overall direction of change was relatively consistent across staff members, in that the majority thought the sleep problem was less likely to be part of the child’s natural sleep cycle post-workshop.

Following the same pattern, the mean response to Item 3 (*sleep problem is a part of the child’s ASD*) was greater at Time 1 ($M = 3.55$, $SD = 0.67$) compared to Time 2 ($M = 2.05$, $SD = 0.38$). However, both the ES ($d = -0.92$), 95% CI $[-1.5, -0.33]$, and CLES (77%) for this comparison were smaller compared to previous items. Twelve staff members reported a decrease in agreement with this item following the workshop, while the remaining 10 staff members did not change their response. Before the workshop, responses ranged from ‘*disagree*’ (n=1) to ‘*strongly agree*’ (n=1), with the majority of responses clustered around

‘*somewhat agree*’ (n=10) and ‘*agree*’ (n=10). After the workshop, this range decreased slightly, to between ‘*disagree*’ (n=1) and ‘*agree*’ (n=2) and the most common response was ‘*somewhat agree*’ (n=19). Compared to previous items, the direction of change for Item 3 was less consistent, with only 55% of staff indicating a change in the hypothesized direction (i.e. a decrease in belief that the sleep problem was part of the child’s ASD following the workshop).

In line with results from the previous three vignettes, the mean staff member response to Item 4 (the *behaviour is learnt and can be changed*) was lower at Time 1 ($M = 3.36$, $SD = 0.73$) in comparison to Time 2 ($M = 4.23$, $SD = 0.43$), ES ($d = 1.45$), 95% CI [0.78, 2.1]. The CLES for this item was 88%. At Time 1, responses ranged from ‘*disagree*’ (n=2) to ‘*strongly agree*’ (n=1), with ‘*somewhat agree*’ being the most common response (n=11). Following the workshop, the distribution of responses became much more clustered, with the only two responses given being ‘*agree*’ (n=17) and ‘*strongly agree*’ (n=5). This shift in distribution was caused by the 16 staff members who reported an increase in agreement with this item post-workshop. The remaining five staff members did not change their response. Thus, the dominant trend displayed by staff was an increase in belief that the sleep problem was learnt and could be changed following the workshop.

Lastly, the mean response to Item 5 (*parent change leads to change in behaviour*) was also lower at Time 1 ($M=3.46$, $SD = 0.67$) than Time 2 ($M = 4.36$, $SD = 0.49$). The ES for this comparison was large ($d = 1.55$) at 95% CI [0.86, 2.21]. The CLES for this item was also high, at 91%. Prior to the workshop, the distribution of responses ranged between ‘*somewhat agree*’ (n=14), which was also the most commonly given response, to ‘*strongly agree*’ (n=2). Following the workshop, 16 staff members increased their level of agreement with Item 5 and six staff members did not change their response. As a result, the distribution at Time 2 was less spread and clustered towards higher scores (indicating high levels of agreement).

Responses at this time-point ranged from '*agree*' (n=14) to '*strongly agree*' (n=8). This suggests that staff members were more likely to believe that the sleep problem would change if parent behaviours changed after the workshop compared to beforehand.

Chapter 5

Study One Discussion

Study One was designed to assess the impact of an educational training workshop on residential staff knowledge and attributions about sleep problems in children with developmental disabilities. Study One included the following four research questions:

1. What level of knowledge do staff members working at a residential facility for youth have about sleep problems in children with developmental disabilities?
2. Does attending an educational workshop increase staff members' knowledge of sleep problems?
3. What attributions and beliefs do staff members hold about sleep problems in this population, including their locus of causality, stability, and controllability?
4. Are staff attributions about sleep problems altered as a result of participating in an educational workshop?

This chapter begins by providing a brief discussion of results relating to the research questions stated above. It then goes on to discuss the limitations of the current study and suggests directions for future research.

The findings of this research suggest that residential staff have limited knowledge of sleep problems in children with developmental disabilities. However, results indicate staff members' level of knowledge increased following participation in a two-hour educational workshop. Findings also suggest that staff members originally attributed sleep problems to factors that were internal, unstable and yet controllable. Following the workshop, these attributions shifted to the extent that staff members attributed sleep problems to factors that were external, stable and controllable.

Staff knowledge about sleep problems. Based on previous research investigating knowledge of sleep problems in parents (Richdale & Robinson, 2004; McDowall et al., 2017;

Owens et al., 2011; Shreck & Richdale, 2011), it was hypothesized that staff members would have limited to moderate levels of knowledge about the prevalence, cause, assessment and treatment of sleep problems. The data obtained by the current study are consistent with this hypothesis. Prior to the workshop, the 24 staff members included in this study displayed limited knowledge of the type, prevalence, etiology, assessment and treatment of sleep problems in children and adolescents with developmental disabilities. The majority of staff members responded correctly to questions about the secondary impacts of sleep problems and factors associated with developmental disabilities that can contribute to sleep problems. By contrast, common errors related to the prevalence, assessment and treatment of sleep problems. Staff members in the current study also tended to over- or underestimate the amount of sleep children need.

This is the only study identified that has examined residential care staff's knowledge of sleep and sleep problems. However, the findings do align with previous research examining parents' knowledge of children's sleep problems. These earlier studies reported that parents had limited understanding of the etiology, prevention, and treatment of child sleep problems (Kanis et al., 2015; Richdale & Shreck, 2011). The lack of awareness of age-appropriate sleep durations has also been commonly observed in previous studies conducted with parents (McDowell et al., 2017; Owens et al., 2017; Richdale & Shreck, 2000). However, while staff knowledge of sleep problems was limited, it was comparatively higher when compared to the research examining sleep knowledge among parents (McDowall et al., 2017; Owens et al., 2011; Richdale & Shreck, 2011).

While these findings suggest that staff members working in residential care facilities have a better understanding of childhood sleep problems when compared to parents, 50% of staff members were unable to answer more than half of the questions included in the questionnaire correctly. These findings are important, as a lack of knowledge regarding the

prevalence and presentation of sleep problems may mean staff members are less able to recognize sleep problems in children for whom they care. As a result, sleep problems experienced by these children might be left untreated. Furthermore, a basic knowledge of sleep hygiene is critical to ensuring a sufficient quality and quantity of sleep (Jan et al., 2008; Vriend et al., 2011). A lack of knowledge about some of the key features, causes of sleep problems and the principles that underpin good sleep may have detrimental effects on the wellbeing of the children for whom they care. In previous research, a lack of parent knowledge has been associated with poorer sleep outcomes, such as short sleep duration, and unhealthy sleep practices, including irregular or late bed times and use of electronic devices in bed (Owens et al., 2011). The observed lack of staff knowledge in relation to age-appropriate sleep requirements also has important implications as it may cause staff to have unrealistic expectations about how much sleep children need. As a result, children might be put to bed too early, or be expected to remain in bed too long, which can result in sleep problems such as sleep onset delay or early morning waking. Conversely, if staff members underestimate a child's sleep needs it can result in problems related to fatigue.

Given that sleep problems have been associated with impaired daytime functioning and internalizing and externalizing symptoms (DeVincent et al., 2007; Goldman et al., 2011; Hollway & Aman, 2011; Paavonen et al., 2009; Richdale & Shreck, 2009; Vriend et al., 2011), it is ideal that they are identified, assessed, and treated appropriately. Furthermore, to reduce the likely development and maintenance of sleep problems, it is also beneficial that staff members are aware of age-appropriate, healthy sleep patterns. It is therefore important to ensure that residential staff that care for children and adolescents with developmental disabilities, and who are particularly vulnerable to sleep problems, receive adequate training in sleep and sleep problems.

It was hypothesized that the workshop would increase staff members' knowledge of sleep and sleep problems in children and adolescents with developmental disabilities. Findings confirmed this hypothesis, with 22 out of 24 staff members displaying an increase in knowledge following participation in the workshop. Although this is the first known study to investigate the impact of an educational workshop on the sleep knowledge of residential care staff who work with people with developmental disabilities, the findings from this study are in line with previous research investigating the effect of group-training interventions on parents' knowledge of sleep. These studies found that interventions that deliver information about sleep and sleep problems in children via a group workshop format are effective in increasing parents' knowledge of sleep (Johnson, Turner, Foldes, Brooks, Kronk & Wiggs, 2014; McDowall et al., 2017; Stores & Stores, 2004; Wilson, Miller, Bonuck, Lumeng & Chevrin, 2013). The current study, along with prior research findings, suggest that a short educational workshop delivered via group format is an efficient, cost-effective way of educating staff about sleep problems. Given the implications of insufficient sleep, and significant impact of sleep problems, it is important to consider routinely providing this type of training for staff who work with children with developmental disabilities.

Staff attributions about sleep problems. Residential staff members' attributions about sleep problems have not previously been assessed. However, given the attributions and beliefs of parents of those with developmental disabilities and sleep problems, it was hypothesized that staff members would attribute sleep problems to factors that are internal, stable and uncontrollable. By contrast, the results of this study indicate that prior to the workshop, the majority of staff members attributed sleep problems to factors that were internal, unstable and yet controllable. This pattern of attributions was observed for three of the four vignettes included in the *Staff Attribution Questionnaire*.

The finding that staff attributed sleep problems to factors that were unstable was surprising, as it does not align with previous research conducted with parents of children with developmental disabilities. These studies reported that parents were likely to attribute their children's sleep problems to factors that were stable (Bessey et al., 2013; Hartley et al., 2013; Kennan, 2006). One explanation for this observation is that staff members believe that children can outgrow the sleep problems. This belief has previously been observed among parents (Robinson & Richdale, 2004; Wiggs & Stores, 1996). The fact that staff attributed sleep problems to factors that were unstable is important, as it may cause a delay in accessing treatment (Robinson & Richdale, 2004; Wiggs & Stores, 1996). Research has shown that sleep problems in children with developmental disabilities are unlikely to resolve without treatment, and if left untreated, tend to persist into adolescence and even adulthood (Baker et al., 2013; Deliens et al., 2015; Goldman et al., 2011; Limoges et al., 2005; Richdale, 2013; Richdale & Shreck, 2009). The current findings suggest that residential staff are not aware of this pattern, and instead believe that the sleep problems will resolve over time. As a result, staff members are unlikely to recognize the importance of intervention for sleep problems and may not seek treatment when necessary. If left untreated, not only will these sleep problems persist, they may also have a long-term, negative impact on children's overall wellbeing and daytime functioning (DeVincent et al., 2007; Goldman et al., 2011; Hollway & Aman, 2011). It is therefore important that staff receive training about the persistence of sleep problems across the lifespan and the fact that they are unlikely to resolve without treatment.

The finding that staff attributed sleep problems to factors that had an internal locus (such as the child's natural sleep cycle and ASD diagnosis) is in line with previous research conducted with parents of children with developmental disabilities (Bessey et al., 2013; Didden et al., 2002; Hartley et al., 2013; Keenan, Wild, McArthur & Epsie, 2006;

McDougall, Kerr & Epsie, 2005). This finding is important, as research conducted with parents suggests that intrinsic attributions about a child's behaviour can negatively influence how effective parents think treatment will be (Dardennes et al., Keenan et al., 2006). If staff do not perceive treatment for sleep problems to be effective, they are not likely to seek it. Once again, this may mean that sleep problems go untreated in the children for whom staff care.

Somewhat contradictory, however, the current study found that staff attributed sleep problems to factors that were controllable. This finding is in contrast with previous research, which indicates that parents of children with developmental disabilities tend to see their children's sleep problems as change resistant (i.e. not controllable) (McDougall et al., 2005; Bessey et al., 2013; Hartley et al., 2013; Keenan et al., 2006). The fact that staff perceived sleep problems in children with developmental disabilities to be controllable is promising, as this may positively influence their openness and engagement with behavioural interventions.

There are several possible explanations for these findings, and for why they differ from research conducted with parents. The first is that staff members' attributions are influenced by their experience. It is likely that the staff members included in this study have worked with and cared for a number of children and adolescents with developmental disabilities. As a result, staff perspectives and attributions are likely to differ from those of parents, who typically have less experience with this population. Second, compared to parents, residential staff members are more likely to have either been involved in, or observed behavioural interventions for problem behaviours in those with developmental disabilities before. If staff have previously observed success from behavioural interventions for alternative behaviours, they will be more likely to believe that sleep problems could also be altered by a behavioural treatment approach. These factors would explain why compared to parents, staff were more likely to attribute sleep problems to factors that were controllable.

An interesting finding from the current study was that vignette three, which described a boy with ASD who was engaging in sleep interfering stereotypic behaviour, was somewhat of an anomaly. For this vignette, staff members tended to attribute the behaviour to factors that were intrinsic, stable and uncontrollable. These attributions differ from those reported for the other three vignettes, where staff attributed sleep problems to factors that were unstable and controllable. These attributions align with findings of previous research that suggest parents of children with developmental disabilities typically attribute sleep problems to factors that have an internal locus (i.e. a feature of the child's diagnosis), are stable and uncontrollable (Bessey et al., 2013; Didden et al., 2002; Hartley et al., 2013; Kennan et al., 2006; McDougall et al., 2005). It is possible that the pattern of attributions observed for vignette three is associated with the fact that stereotypic behaviour represents a core behavioural symptom of ASD (Bailey et al., 2019; Emerson, 2003). It is therefore logical that, compared to the behaviours described in the other vignettes (e.g. anxiety, co-sleeping, bedtime resistance), staff members were more likely to attribute sleep-interfering stereotypy to the child's diagnosis, and therefore more stable. Research among parents has also shown that the more strongly parents attribute their children's behaviour to their diagnosis (i.e. of internal locus), the less controllable they perceive the behaviour to be (Keen et al., 2006). Findings from the current study support this relationship. It is also possible that staff members' attributions were influenced by previous experience in trying to treat stereotypy, as the treatment of this type of behaviour can be especially difficult, and often requires a high level of clinical involvement (Grahame et al., 2015).

The fact that staff attributed sleep-interfering stereotypy to factors that were stable and uncontrollable has important implications for the treatment of sleep problems in children and adolescents who live in residential care. If staff members do not see sleep problems such as sleep-interfering stereotypy as controllable behaviours, it is unlikely that they will seek

treatment for them, even though stereotypy can be treated with behavioural intervention (Matson, Dempsey & Fodstad, 2009). It is therefore important that residential staff are informed about the effectiveness of behavioural interventions in the treatment of a range of sleep problems, including sleep-interfering stereotypy.

It was hypothesized that the workshop would alter staff members' attributions and beliefs about sleep problems. The anticipated direction of this change was such that after participating in the workshop, staff would be more likely to see sleep problems in children with developmental disabilities as attributable to extrinsic, as well as intrinsic factors (i.e. locus), chronic when left untreated (i.e. stable), and responsive to treatment (i.e. controllable). Findings were in line with this hypothesis, and indicated that, following the workshop, staff members were more likely to attribute sleep problems to factors other than those intrinsic to the child (such as their ASD diagnosis and natural sleep cycle), that were stable (without treatment), yet controllable. These changes in staff attributions were highly consistent across both staff members and vignettes.

The observed shift in staff attributions is most likely explained by the concurrent increase in knowledge associated with participating in the workshop. For example, during the workshop staff were made aware that in addition to having a biological component, research has shown that sleep problems also have environmental and behavioural underpinnings, both of which are of external locus (Richdale & Shreck, 2009; Blampied & France, 2013; Galland & Mitchell, 2010; Hollway & Aman, 2011). It is therefore unsurprising that increasing staff members' awareness of how external factors can influence sleep was associated with a shift away from internal locus of attribution. The workshop also informed staff of the persistent nature of sleep problems in those with developmental disabilities and highlighted the availability of a number of effective behavioural interventions. It is likely that the provision

of this information contributed to the observed change in staff attributions regarding the stability and controllability of sleep problems in this population.

To the researcher's knowledge, this is the first study to investigate the impact of an educational workshop on either parent or staff member attributions and beliefs about sleep problems (or any other behavior) in children with developmental disabilities. The current study indicates that educating staff members about sleep problems can alter their attributions regarding the locus, stability and controllability of these behaviours. This finding has important implications for the treatment of sleep (and other) problems in this population. To reduce the risk of attributional biases negatively influencing staff members' willingness to seek treatment, or their engagement with the treatment process, it is crucial that staff attributions be addressed. The current study indicates that the inclusion of an educational component within group-delivered intervention and/or training programmes is an effective way to do so.

Limitations

The current study had three notable limitations. The first limitation relates to the use of Likert scales. Likert scales were included in the current study due to their ease of administration, response and interpretation (Pornel & Saldaña, 2013). However, the validity of data collected using Likert scales is limited in two key respects. First, it is well documented that the upper and lower ends of Likert scale responses are less likely to be used than more centrally located choices (Bishop & Herron, 2015). Thus, staff members may have avoided choosing either 'strongly disagree' or 'strongly agree', even if this would be the most accurate representation of their attitude toward the item. Secondly, the mid-point response included in five-point Likert scales is often incorrectly perceived by respondents as being synonymous with 'I don't know', or indicating indifference (Hodge & Gillespie, 2003;

Pornel & Saldaña, 2013). In the current study, the mid-point response was labeled ‘*somewhat agree*’. Nevertheless, it is possible that staff members may have also used this response for items of which they were unsure. These factors could hinder the validity of data collected from the *Staff Attribution Questionnaire*, as they may mean that the responses given by staff members were not an accurate representation of their true attributions.

The second limitation of this study is the lack of follow-up data. Findings from research investigating the effects of educational interventions on the sleep knowledge of parents indicate that the increase in knowledge acquired during training may not be maintained at long term follow up (e.g. six to 12 months later) (Johnson et al., 2014; Stores & Stores, 2004; Wilson et al., 2014). Therefore, it would have been beneficial to collect follow-up data to ascertain whether treatment effects observed in the current study follow a similar pattern, or whether the increase in staff knowledge is maintained long-term.

A third limitation of the current study is that the questionnaires used were not standardized measures, but were created by the research team. As a result, the reliability and validity of the measures used in this study is unknown. It is important that this lack of validity and reliability data is taken into consideration when interpreting the current study’s findings.

Future Directions

The findings of the current study, along with the associated limitations, highlight a number of important avenues for future research. First, a more thorough investigation into residential staff knowledge of sleep problems and related attributions is warranted. Future research in this area should employ other measures in addition to Likert-scale ratings to assess staff member attributions of sleep problems. Doing so may provide further insight into staff members’ beliefs and attributions about sleep problems in those with developmental

disabilities. In addition, future research should employ a more rigorous and comprehensive assessment of staff sleep knowledge. One way to do this would be to use a questionnaire that includes a greater number of items, and uses subscales. The *Staff Knowledge Questionnaire* employed in the current study was purposefully brief in order to allow for the staff members' very limited time availability. However, a longer questionnaire that is divided into subscales would help researchers to clearly identify areas of strength in relation to staff members' knowledge of sleep problems, and areas where knowledge is particularly lacking. The use of subscales would also help to establish which specific areas of sleep knowledge are most responsive to this form of training, and which topics require a more thorough explanation. While there is no standardized measure of sleep knowledge for staff or parents, future research may adapt the *Parents' Sleep Knowledge Inventory (PSKI)*, which was created and implemented by Shreck and Richdale (2011). The PSKI is a 62-item questionnaire that assessed parent knowledge of the BEARS sleep domains (e.g. bedtime problems, excessive daytime sleepiness, awakenings during the night, regularity and duration of sleep, and snoring) (Shreck & Richdale, 2011).

Secondly, future research should attempt to identify whether changes in staff members' knowledge and attributions as a result of group training are maintained. Research conducted with parents indicates that the long-term maintenance of treatment effects resulting from this intervention approach may require a more thorough intervention approach that spans a longer period of time. Taking this into account, it is important that future studies include a follow-up phase in order to establish the long-term impact of staff-training interventions that are designed to increase understanding of sleep problems in those with developmental disabilities.

Lastly, it is possible that the observed impact of intervention is isolated to the current study population. Thus, another recommendation for future research would be to expand this

study to a wider demographic. For example, it would be beneficial to understand the knowledge and attributions of non-familial groups, such as medical practitioners or social workers, and examine how group-delivered educational workshops alter such factors in these groups. It is likely that such sample populations will have varying capabilities and experience with sleep problems in those with developmental disabilities, and including them in future research would help to identify whether results can be generalized to the wider population.

Conclusion

The current study sought to assess residential staff knowledge of sleep problems and their related attributions. The study also examined the effect that participating in the workshop had on staff knowledge of sleep problems in those with developmental disabilities, and the attributions that they made regarding their locus, stability and controllability. Findings indicate that residential staff have limited knowledge of sleep problems, and tend to attribute sleep problems in children and adolescents with developmental disabilities to factors that are intrinsic, unstable and uncontrollable. The current study also provides evidence to support the effectiveness of an educational group-training approach in increasing staff knowledge, and shifting their attributions about sleep problems in this population. Following the workshop, staff members were more able to correctly answer questions regarding the prevalence, cause, assessment and treatment of sleep problems in children with developmental disabilities. Following the workshop, staff members were also more likely to attribute sleep problems in those with developmental disabilities to factors that were extrinsic, stable (without treatment) and controllable. Such findings add to the current literature supporting the effectiveness of group-administered training programmes in increasing the sleep knowledge of staff, and extends this research to suggest that such programmes also alter staff attributions about sleep problems. Collectively, these findings have a number of important implications for the training of residential staff in regard to sleep,

and also the implementation of sleep interventions within the residential environment. Future research should endeavour to further investigate this topic, specifically to address the long-term impact of this intervention approach.

Chapter 6

Study Two Method

Study Two evaluated the effectiveness of FBA-informed, staff delivered, behavioural intervention in treating sleep problems in three children with developmental disabilities and sleep problems, who were living in residential care. For information regarding the ethics, setting, recruitment and consent, or participant anonymity and confidentiality for Study Two, please refer back to Chapter 2.

Study Design

This study used a single case multiple baseline across participants research design. This means that individual change was measured by comparing data recorded at baseline with data collected post-treatment. In studies using a single case research design, each individual acts as their own control, meaning that no individuals are placed in a waitlist or ‘control group’ before receiving treatment (Blampied, 2013). The use of multiple baseline design has two key advantages. First, the use of multiple participants allows for replication of an experiment and thus enables conclusions to be made about the generalizability of treatment effects (Moeyaert, Maggin & Verkuilen, 2016; Blampied, 2013). Secondly, the scattering of treatment phases between participants enables treatment effects to be observed across different points in time (Blampied, 2013). This increases confidence that observed changes are due to the treatment itself and not due to external factors, thus increasing internal validity.

Participants

Recruitment. As the facility approached the research team requesting staff training and support no participant recruitment was required.

Inclusion and exclusion criteria. Children were eligible for inclusion in this study

if they met the following criteria: (a) aged between 5-19 years of age; (b) had a developmental disability as verified by a paediatrician, psychiatrist or psychologist; (c) experienced sleep disturbance, as reported by staff members (e.g. sleep onset delay, bedtime resistance, night-waking, unwanted co-sleeping); and (d) lived in a house for which staff members and house manager had consented to participate in the study.

Children were excluded from the study if: (a) they had a comorbid physical or medical condition that may have compromised the effectiveness of treatment, or that made the implementation of a sleep intervention unsafe (e.g. nocturnal seizure disorder, obstructive sleep apnea); (b) if they were in a residential house where staff did not consent to participating in the study; or (c) if researchers could not obtain parental consent.

Participant characteristics. Participants included three males, whose ages ranged from 10 years and 11 months to 17 years and 8 months. To protect their anonymity, each of these participants has been assigned a pseudonym. All three participants had a diagnosis of both ASD and intellectual disability. At the time the study commenced, two out of three of the participants were taking medication. This included melatonin and fluoxetine. A summary of participant characteristics is displayed in Table 1.

Table 1

Summary of Participant Characteristics for Study Two

Name	Gender	Age (Y)	Sleep Problems	Diagnosis	Medication
Harry	Male	17	Sleep onset delay	ASD, ID	None
William	Male	12	Sleep onset delay, early morning waking	ASD, ID	Melatonin
Steven	Male	10	Sleep onset delay, curtain calls	ASD, ID	Fluoxetine

Setting

The initial interviews with residential house managers were completed either over the phone or in person at the residential care facility. Data collection during assessment, baseline and intervention phases took place at the residential facility. Parents of children were contacted either over the phone or via email. It was necessary for these discussions to be carried out remotely as the children at the facility came from various regions.

Staff members working at the facility implemented interventions in three different houses. The number of children in each house ranged from four to six. During the day approximately five staff members were present in each house, while at nighttime (from 9.00pm to 7.00am) children were supervised by one to two staff members. The house manager for each participant lived in an adjacent house and was therefore available to support staff members at all times if needed.

Measures

The research team typically uses video recording, actigraphy (a small, watch-like device that records movements associated with sleep and can be worn on the ankle or wrist) and sleep diaries to assess and monitor the sleep patterns of participants. However, during initial discussions with the residential manager, it was deemed that due to the communal nature of the setting, the use of video recording would not be appropriate. In addition, house managers felt that actigraphy would not be tolerated by any of the three participants. In the absence of these measures, the sleep patterns of participants were measured using a combination of staff member reported sleep diaries and behaviour scatterplots (an existing behaviour recording procedure used at the facility).

Staff member-reported sleep diaries. Sleep diaries are commonly used to measure the sleep patterns of typically developing children and children with developmental

disabilities (Blampied, 2013; France & Blampied, 2005; McLay & France, 2014). In the current study, sleep diaries were the primary sleep outcome measure. As part of the workshop outlined in Study One, staff members were shown an example of the sleep diaries that were to be used (see Appendix J) and were shown how to complete them correctly. Staff members were then provided with hard copies of the sleep diaries and house managers were sent a digital copy via email. The data recorded in the sleep diaries included: (1) information regarding children's day-time sleep: including the setting, time and duration of sleep; (2) the child's night-time sleeping patterns: such as sleep setting, time put to bed, curtain calls (frequency, nature and staff response), and the best estimate of the time that the child fell asleep; (3) night-time awakenings (time and duration of awakening, nature and response of staff members); and lastly (4) time of waking in the morning. Researchers asked staff members to record sleep diaries on a daily basis during assessment, baseline and intervention phases. To ensure close monitoring of participants' sleep, and to enable any necessary changes to participants' treatment plan to be made in a timely manner, the research team requested that diaries be returned on a weekly basis, via email.

Behaviour scatterplots. At the residential care facility where the study took place it was protocol for staff members to keep a record of residents' behaviour both during the day and throughout the night. To do so, the facility used 'behaviour scatterplots'. To complete the behavioural scatterplots, staff members were required to observe, code and record each resident's behaviour at half-hour intervals. The data were presented by month, in the form of a table, with columns representing days of the month, and rows representing half hour intervals. The scatterplots for night-time behaviour began at 9.00pm and ended at 7.00am. Types of behaviours that were recorded in the night time behaviour scatterplots include: (a) Challenging behaviours; (b) if the child was awake; (c) when child was out of bed; (d) bed wetting; (e) faecal smearing; (f) the occurrence of seizures; (g) if the child was unwell; and

(h) if the child was making noise. If during the night the child was not displaying any of the behaviours listed above when observed by staff, it was simply recorded that the child was checked. For the purpose of the current study, if a child was checked during the night and was not displaying any visible behaviour, then in-line with staff reporting, it was assumed that the child was asleep. The information recorded in these night-time behaviour scatterplots was used where possible in the current study to supplement data from sleep diaries.

Sleep assessment measures. To inform the assessment of participants' sleep patterns, the following three psychometric measures were used.

Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito & McGuinn, 2000).

The CSHQ is a caregiver report measure used to assess sleep problems children aged 4 to 10 years of age, and was administered to one participant. The purpose of this was to identify any behaviorally or medically based sleep problems among participants. The CSHQ was completed by the residential house manager for each participant (Malow et al., 2014; Owens, et al., 2000). The CSHQ comprises 45 items and produces both a total score and eight subscale scores. These subscales reflect the key domains of sleep disorders observed in children, including: (1) Sleep onset delay; (2) bedtime resistance; (3) sleep anxiety; (4) sleep duration; (5) parasomnias; (6) night wakings; (7) daytime sleepiness; and (8) disordered breathing (Owens et al., 2000). The CSHQ is retrospective in nature as items ask caregivers to report the frequency with which a child has displayed a sleep behaviour in the past week. Caregivers respond to items using a three-point Likert scale: 1 = rarely (zero to one night per week), 2 = sometimes (two to four nights a week) or 3 = usually (five to seven nights a week). A clinical cutoff score of 41 is indicative of a sleep problem, and a higher total CSHQ score reflects greater sleep problems.

The CSHQ shows good psychometric properties when used with typically developing children and children with developmental disabilities (Hoffman et al., 2006; Johnson et al.,

2016; Malow et al., 2014; Owens et al., 2000). Owens and colleagues (2000) reported satisfactory rates of internal consistency among both community ($p = 0.68$) and clinical samples ($p = 0.78$), and a test-retest reliability of 0.79. Furthermore, the CSHQ has a sensitivity of 0.80, and specificity of 0.72, indicating that it is able to consistently differentiate between healthy sleepers and those who are sleep disordered (Owens et al., 2000).

Sleep Disturbance Scale for Children (SDSC; Bruni et al., 1996). The SDSC was used to identify specific sleep disorders and overall level of sleep disturbance among participants. The SDSC is suitable for children between the ages of 5.8 to 15.5 years old, and was completed for the two participants who were within this age range. The SDSC is a caregiver-report measure used to categorize sleep disorders in children (Bruni et al., 1996). The questionnaire includes 27 items, all of which require respondents to use a five-point Likert scale (1= never, 2= occasionally, 3 = sometimes, 4 = often, 5 = always) to indicate the frequency of specific sleep related behaviours displayed by the child in the past six months (Bruni et al., 1996). In addition to yielding an overall score, the SDSC produces six subscale scores across the domains of: (1) Disorders of initiating and maintaining sleep; (2) sleep breathing disorders; (3) disorders of arousal; (4) sleep-wake transition disorders; (5) disorders of excessive somnolence; and (6) sleep hyperhidrosis (Bruni et al., 1996). The SDSC has shown good psychometric properties (Bautista, Whittingham, Edwards & Boyd, 2017; Bruni et al., 1996; Lecuelle et al., 2020). Bruni et al. (2000) reported high internal consistency in both control ($r = 0.79$) and sleep disordered groups ($r = 0.71$), and a test-retest reliability of 0.71.

Adolescent Sleep Hygiene Scale (ASHS; LeBourgeois et al., 2005). The ASHS was administered during baseline phase to assess participants' sleep hygiene practices. The ASHS is suitable for individuals over 12 years old, and was administered to one participant who fell

within this age range (LeBourgeois et al., 2005; Storfer-Isser, LeBourgeois, Harsh, Tompsett & Redline, 2013). The ASHS is a 33-item questionnaire that assesses aspects of sleep hygiene that are thought to influence the sleep quality and quantity of adolescents, including physiological, cognitive and emotional factors, sleep environment, substance use, bedtime routine, daytime sleep, sleep stability and bed sharing (LeBourgeois et al., 2005).

Respondents are asked to rate on a six-point Likert-scale how often they have engaged in certain activities (e.g. taking a nap, smoking tobacco, engaging in physical activity etc.) within the past month. Possible responses included never, once in a while, sometimes, quite often, frequently or always. The ASHS displays strong psychometric properties, with studies reporting overall internal consistencies between $\alpha = 0.80$ and $\alpha = 0.84$ (de Bruin, van Kampen, van Kooten & Meijer, 2014; Ji & Liu, 2016; LeBourgeois et al., 2005; Sttorfer-Isser et al., 2013). The ASHS has also demonstrated appropriate concurrent and convergent validity (de Bruin et al., 2014; Sttorfer-Isser et al., 2013). For example Sttorfer-Isser and colleagues (2013) found total scores on the ASHS to be positively correlated with sleep duration ($\alpha = 0.16$) and sleep efficiency ($\alpha = 0.12$), and negatively correlated with factors such as sleep onset latency ($\alpha = 0.14$).

Assessment of daytime functioning. The following six psychometric measures were completed by the house managers during assessment phase and used to inform researchers understanding of participants' level of ability and identify any additional challenging behaviour that might influence intervention.

Vineland Adaptive Behaviour Scales 3 (VABS-3) – Comprehensive Caregiver Form; Sparrow, Chicchetti & Saulnier, 2016. The VABS-3 was used to assess participants' level of receptive and expressive language. This caregiver-report measure is designed to assess adaptive behaviour across the following five domains: communication, daily living,

socialisation, motor skills and maladaptive behaviour (Sparrow et al., 2016). To complete the VABS-3, respondents were required to indicate on a three-point Likert scale whether, without help from others, participants displayed a particular behaviour (1) often, (2) sometimes or (3) never. For the purposes of the current study, house managers were required to complete only the section of the form that assessed participants' level of communication as this was deemed to be most critical in informing the types of interventions that may be able to be used and the mode in which information was able to be presented to participants (e.g. determining the complexity of language used in a child-specific sleep story). The communication domain consists of three subscales: listening and understanding, talking, and reading and writing. The total number of items in each of these subscales ranged from 38-49. The VABS-3 comprehensive caregiver form has strong psychometric properties, with the communication domain yielding an internal consistency of $r = 0.97$ and test-retest reliability of $r = 0.88$ (Saulnier, 2016; Sparrow et al., 2016).

Child Behaviour Checklist (6-18 years) (CBCL; Achenbach & Rescorla, 2000). The CBCL was administered during baseline phase as a measure of participants' daytime behaviour. This 100 item parent report measure provides information regarding children's psychiatric and somatic symptomology (Achenbach & Rescorla, 2000). Respondents are presented with descriptions of specific behaviours (e.g. argues a lot) and asked to rate how accurately this reflects the behaviour of the child on a 3-point Likert scale (0 = not true, 1 = sometimes or sometimes true or 3 = very or often true). The CBCL produces scores on seven empirically-based syndrome scales: aggressive behaviour, anxious/depressed, withdrawn, attention problems, emotionally reactive, somatic complaints and sleep problems, and five DSM-5 related scales: ASD, anxiety, depression, ADHD and oppositional defiance. These syndrome scales are then categorized and combined to form a score for internalizing problems, externalizing problems and a total problem composite score. Finally, T-scores are

used to calculate whether the child's scores reflect normal, borderline or clinical behaviour (Achenbach & Rescorla, 2000). Studies have reported favourable psychometric properties for the CBCL when used with both typically developing children and those with developmental disabilities (Berubè & Achenbach, 2010; Pandolfi, Magyar & Dill, 2012; Pandolfi, Magyar & Norris, 2014). Pandolfi and colleagues (2012) found all eight subscales to be internally consistent, with correlations ranging between $r = 0.80$ and $r = 0.89$. Adequate levels of concurrent validity have also been reported, with scores on the CBCL positively correlating with scores on the equivalent domains within the *Schedule for Affective Disorders and Schizophrenia-Childhood Version*, with correlations ranging from $r = 0.39$ to $r = 0.65$.

Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001). The SDQ is a behavioural screening tool that can be completed by caregivers, and was used in the current study to measure participants' behaviour problems. Both the child (for children between 4-16 years of age) and adolescent (for ages 11 – 17 years) versions were used. The SDQ contains 25 items, which require respondents to rate their responses on a 3-point Likert scale according to the extent to which a specific attribute applies to the target child (0 = not true, 1 = somewhat true or 3 = certainly true). SDQ items measure children's behaviour across five subscales: conduct problems, hyperactivity, emotional symptoms, peer problems and prosocial behaviour (Goodman, 2001). The SDQ was administered to all participants. Numerous studies have found that the SDQ has adequate psychometric properties, including a good internal consistency ($\alpha = 0.79$) and test-retest reliability of $\alpha = 0.62$ (Goodman, 2001; Hawes & Dadds, 2004; Husky, 2018; Kersten et al., 2015). There is also evidence to support the convergent and divergent validity of the SDQ (Kersten et al., 2015).

Gilliam Autism Rating Scale – Third Edition (GARS-3; Gilliam, 2016). The GARS-3 was administered during assessment to measure the severity of ASD symptoms displayed

by participants. The GARS-3 is a parent or professional report measure that can be used with individuals between 3-22 years of age. The GARS-3 contains a total of 56 items and assesses behaviour across six domains: social interaction, restricted/repetitive behaviours, emotional response, social communication, maladaptive speech and cognitive style (Gilliam, 2016). These subscales reflect the DSM-5 diagnostic criteria for ASD (American Psychiatric Association, 2013). Each item describes a particular observable behaviour (e.g. making high-pitched sounds), and respondents are required to rate how adequately it describes the individual. The GARS-3 provides a Likert scale for respondents to do so, indicating that the behaviour is: 0 = not at all like the individual, 1 = not much like the individual, 2 = somewhat like the individual, or 3 = very much like the individual. Raw scores are converted and summed to yield an overall Autism Index Score, with higher scores indicating greater ASD symptom severity (Gilliam, 2016). The GARS-3 displays high levels of reliability, as indicated by internal consistency and test-retest reliability data (Gilliam, 2016; Karren, 2017). For example, subscales on the GARS-3 yield internal consistency scores that range between $\alpha = 0.79$ to $\alpha = 0.94$ and a test-retest correlation of $\alpha = 0.90$ has been reported for the measure (Gilliam, 2016; Karren, 2017). Evidence also supports the validity of the GARS-3, with the measure showing excellent levels of sensitivity and specificity (Gilliam, 2016; Karren, 2017).

Multidimensional Anxiety Scale for Children – Second Edition – Parent Form

(***MASC-2; March, 2013***). The MASC-2 was administered to all three participants to assess the presence of symptoms related to anxiety disorders. The MASC-2 is a 50-item comprehensive assessment of anxiety in children and adolescents (between the age of eight to 19 years) (March, 2013). Respondents are asked to complete Likert-style items that relate to the thoughts, feeling and behaviours of the child being observed. The items are rated on a 3-point scale: 0 = never, 1 = rarely, 2= sometimes and 3 = often, with responses reflecting how often each statement is true about the child. The MASC-2 produces an overall Anxiety

Probability Score, as well as a score for the following six subscales: Separation Anxiety/Phobias, Social Anxiety, Generalised Anxiety Disorder Index, Obsessions and Compulsions, Physical Symptoms and Harm Avoidance (March, 2013). Reliability analyses conducted on the MASC-2 parent form suggest that it yields acceptable internal consistency (Fraccaro, Stelnicki & Nordstokke, 2013; March, 2013). Among a normative sample, a coefficient alpha of $\alpha = 0.92$ was calculated for the Overall Anxiety Probability score, while a median value of $\alpha = 0.78$ was calculated for the subscale scores (Fraccaro et al., 2013). Test-retest reliability calculations were reported to range between from $r = 0.80$ to $r = 0.94$, further supporting the reliability of the measure. The MASC-2 parent form has satisfactory concurrent validity levels, showing moderate correlations with similar measures ($r = 0.73$).

Paediatric Quality of Life Inventory – Version 4 – Parent Report Core Scales

(PedsQL™; Varni, Seid & Kurtin, 2001). The PedsQL™ was used to assess participants' health-related quality of life. The PedsQL™ is designed for those aged 2-18 years of age, and was administered to all participants. The parent-proxy report for children (for ages 8-12 years) and adolescents (for ages 13-18 years) were used in the current study. The items for these forms are essentially identical; it is simply the wording that differs, as each form is written in developmentally appropriate language for the corresponding age group (Varni et al., 2001). Each form includes 23 items, each of which describes a possible problem (e.g. forgetting things). These items are categorized into four subscales: physical functioning, emotional functioning, social functioning and school functioning (Varni et al., 2001). Using a five-point Likert scale, respondents are instructed to indicate how problematic a behaviour has been during the past month. Possible responses include: 0 = never, 1 = almost never, 2 = sometimes, 3 = often and 4 = almost always. Items are reverse scored and linearly transformed to a 0-100 scale. Overall scale scores are then calculated by dividing the sum of all item scores by the total number of items answered. Subscale scores are then categorized

to produce an overall psychosocial health score (encompassing emotional, social and school functioning scales) and a score for physical health (which is the same physical functioning scale). Higher scores are indicative of better health-related quality of life.

Satisfactory psychometric properties have been published for the PedsQL™ parent report forms (Varni et al., 2001; Varni, Burwinkle, Seid & Skarr, 2003). For example, Varni and colleagues (2003) reported that for the child and adolescent versions of the parent report measure internal consistency values across subscales were in the range of $\alpha = 0.74$ to $\alpha = 0.92$. The PedsQL™ also shows adequate divergent validity, and was able to differentiate between healthy children and those with chronic health conditions (Varni et al., 2003). Lastly, scores on the PedsQL™ have been found to be negatively associated with indicators of poor health status, such as health care access, school absences and days needing care, therefore supporting the measure's concurrent validity.

Dependent Variables

The combination of dependent variables was different for each child, as they were based upon participant's presenting problems and treatment goals. Dependent variables were recorded nightly, throughout study phases. A brief definition of each of the dependent variables is provided below

Awake. Awake was defined as the child engaging in any sleep-interfering behaviours (such as crying, calling out, or getting out of bed), lying with their eyes open, making excessive movements or making voluntary vocalizations.

Asleep. Asleep was defined as the child lying in bed with their eyes closed, accompanied by the absence of any intentional or voluntary vocalizations or movements.

Sleep-onset delay. Sleep onset latency was defined as the amount of time, in minutes, between when staff members bid the child goodnight and actual sleep onset.

Curtain calls. Curtain calls were classified as any time the child called out or cried while in bed, or got out of bed to actively seek something, such as staff attention or access to a preferred item after being bid goodnight and prior to sleep onset. Each instance of one of these behaviours was recorded as one curtain call (e.g. coming out for a glass of water would represent one curtain call).

Early morning waking. Early morning wakings were defined as when the child woke at least fifteen minutes before the designated (goal) wake-up time. The duration of early morning wakings was measured as the number of minutes between when the child woke up, and the goal wake-up time.

Study Phases

The current study consisted of the following four phases: (1) training workshop, (2) assessment and FBA, (3) baseline and (4) intervention.

Staff training workshop. The current study follows on from the training workshop administered with residential staff in Study One. For information regarding what was included in this workshop, please refer back to Chapter 3.

Assessment and FBA. The assessment phase began immediately after the workshop had been completed. During the assessment phase information was collected to better understand participants developmental histories, past and present sleep patterns and any additional challenging behaviours. This process was conducted using a combination of interviewing, psychometric measures and sleep diaries. The results of this assessment were used to inform the development of comprehensive, individualized treatment plans for each participant. Data collected from psychometric measures during the assessment and FBA phase is presented in Table 2, which can be found in Appendix K.

Staff interviews. The researcher conducted interviews with the residential house manager of each child. These interviews were used to gain an understanding of the history and nature of participant's sleep problems, and to inform the overall functional behavioural assessment (FBA) of these sleep problems. Once protocols relating to consent and confidentiality had been followed, the interview was conducted. The interview followed the format of the Sleep Assessment Treatment Tool (SATT). The SATT is specifically designed to guide the FBA of sleep problems in children and helps to obtain information such as: (a) Sleep problems currently displayed by the child (e.g. night wakings, sleep onset delay or early morning wakings); (b) a history of the child's sleep problems; (c) antecedent conditions or consequential actions that precede or follow the sleep problems; (d) the child's sleep routine and environment; (e) sleep goals; and (f) sleep interfering behaviours or dependencies (Jin, Hanley & Beaulieu, 2013).

Sleep diaries. The sleep diaries completed by staff members were also used to inform the FBA of participant's sleep problems. Information collected in these sleep diaries (e.g. the child's behaviour and the staff member's response to those behaviours), helped researchers to identify antecedent variables and contingencies of reinforcement that may have been maintaining participant's sleep-interfering behaviours. This information was then used to form a hypothesis about the function of sleep interfering behaviour. Possible functions include social attention (e.g. staff member's attention), tangible reinforcers (e.g. access to iPad, food or drink), or escape (being allowed to escape the bedroom). Staff members recorded at least one week of sleep diaries before moving into the baseline phase

Baseline. Participants were randomly assigned a baseline length of either 5, 10 or 15 days. During this time, sleep diary data was collected on a daily basis to enable researchers to observe each child's sleep patterns immediately prior to the introduction of the intervention.

The baseline period was extended if a stable baseline was not established within the given time frame. In order to ensure that the data collected during baseline was an accurate representation of a participant's current sleeping patterns, staff members were asked to continue interacting with participants in the same way they normally would and to make no changes to their night-time routine.

Intervention. Using the data collected during the assessment and baseline phases, and based on the outcomes of FBA, the UC sleep research team collectively developed multimodal sleep treatment plans for each child. Treatment plans were tailored to each child's presenting problem and informed by the treatment goals of their house manager. A key consideration during treatment formulation was the maximisation of treatment acceptability. Therefore, only the least restrictive strategies, such as circadian manipulation and antecedent based modifications (e.g. sleep hygiene and visual supports), were used during the first phase of treatment. The treatment plans for each participant are described in more detail later on in this chapter.

Researchers visited the residential care facility a second time in order to share the proposed treatment plans with staff members in person. The presentation of treatment plans was done in a similar format to the workshop, i.e. researchers held two sessions: one for day staff and one for night staff. During these group sessions, the strategies included in each treatment plan were explained in detail, including how to implement them correctly. A written copy of each child's treatment plan and any necessary resources was also provided to the house managers. To further maximise the social validity of the treatment approach, all staff members were given the opportunity to ask questions about, and provide feedback on each participant's treatment plan. If there were concerns with any aspect of the proposed treatment plans, researchers worked with staff members to adjust the plan to ensure that it

was appropriate for all staff members and participants. Parents were also informed of the treatment plans, either by the researcher or by the child's residential house manager, if the researcher was unable to establish contact.

The date that intervention commenced was determined in consultation with the residential house manager for each child. Residential house managers chose a commencement date that they thought would be best for both staff members and participants in that there were not any current events (such as illness or home visits) that would disrupt treatment. During the intervention phase the research team maintained contact with the house managers via phone and email. The intention of the research team was that the interventions would continue to be implemented until the sleep problems had been resolved, or the house managers withdrew from the study, or the clinical team deemed that it was not in the best interests of the child for the sleep treatment to continue.

Data Analysis

Data obtained from sleep diaries and behaviour scatterplots during assessment, baseline and intervention was graphed according to the dependent variables relevant for each child. Such variables included sleep onset latency (in minutes), frequency of curtain calls and duration of early morning wakings (i.e. time in minutes that the child awoke before the goal wake time each morning). Visual inspection of the graphs was used to examine changes in these sleep patterns between baseline and intervention phases. Visual analysis is commonly employed in single-case multiple baseline designs as it can be used to identify whether behaviour changes are attributed to the treatment (Blampied, 2013; Riley-Tillman & Burns, 2009). To analyze the graphs visually, the level, latency, variability and trend of sleep behaviours are assessed (Cohen, Feinstein, Masuda & Vowles, 2014; Riley-Tilman & Burns, 2009).

In addition to visual inspection, the percentage of data points exceeding the median of baseline phase (PEM) (Ma, 2006) was also used to evaluate the effectiveness of the interventions. The PEM is a non-parametric approach used to evaluate single case experimental designs and is a form of measuring effect size (Ma, 2006). The assumption underlying this method is that if a treatment has no effect, the data points for the intervention phase will fluctuate around the middle; approximately 50% of them will lie above the median of baseline phase and 50% will sit below it (Ma, 2006; Ma, 2009). Therefore, for an intervention that aims to *increase* a specific behaviour, the greater the percentage of data points *exceeding* the median of baseline phase, the more significant the treatment effect. If the intervention is designed to *reduce* a specific behaviour, as in the case of the current study, it is the percentage of data points *below* the baseline median that are used to calculate the PEM. PEM scores are calculated as a decimal, and can range from 0-1. The PEM approach has a number of advantages (Ma, 2006). First, it is easily calculated from graphic displays. Furthermore, unlike other approaches such as the percentage of non-overlapping data approach (PND), the PEM is not affected by ceiling or floor effects, nor by outliers, making it less susceptible to Type II error (Ma, 2006; Ma, 2009). PEM scores are also strongly correlated with the author's judgment regarding the impact of treatment, suggesting that it is an accurate indicator of treatment effects (Ma, 2006). Lastly, PEM scores are easy to interpret qualitatively: a PEM score of 0.50 or less is indicative of a non-effective treatment, a score of 0.50-0.69 signals that the intervention was debatably effective, 0.70-0.89 suggests moderate effectiveness, and if an intervention produces a score of 0.90 it is deemed to be highly effective (Lenz, 2013; Ma, 2006; Scruggs & Mastropieri, 1998).

Results from FBA and Description of Intervention

The following section will provide a brief description of each participant's presenting concerns, results from FBA and their intervention plan.

Harry.

Presenting concerns. Harry was a 17-year-old boy who presented with problems related to sleep onset delay and sleep-interfering behavior that occurred during the sleep onset period. Harry had a relatively consistent bedtime routine, in that the activities he engaged in prior to going to bed did not change (e.g. each night he would have dinner, shower, sit in the lounge, go to toilet and then get into bed). However, the time he was put to bed varied between 8.00pm and 9.00pm. Once instructed to go to bed, Harry would take between three and three and-a-half hours to fall asleep, typically initiating sleep between 12.00am to 12.30am. In the time between when Harry was put to bed and when he fell asleep, he would attempt to get out of bed and walk in to the lounge, sometimes bringing his blanket. Once in the lounge, Harry would engage in motor stereotypy (i.e. he would repeatedly rock back and forth with his blanket wrapped around him). It was also noted that Harry would often appear frustrated by his hair getting in his face, and would repeatedly pull at it. Harry's house manager reported that on occasion, approximately two or three times a month, there would be nights where Harry would not sleep at all. Harry was typically woken between 7.00am and 7.30am, but would often struggle to wake up, and at times would become aggressive toward staff members.

These sleep problems were described by staff members as chronic, and had been occurring since Harry first arrived at the facility five years ago. In a bid to signal to Harry that it was time to sleep, staff would ensure that all lights were turned off and curtains were drawn around the house by 9.00pm. To manage Harry's sleep problems, staff members would allow Harry to leave his room, but would attempt to gently encourage him to return to bed every fifteen minutes by instructing him to go back to his bedroom as it was time for sleep. While Harry might initially go back to bed when instructed, as soon as staff bid him goodnight and shut the door he would return to the lounge. Staff members had determined

that allowing Harry to take himself to bed in his own time when he felt ready to fall asleep, was the only way to manage his sleep-interfering behaviour. Harry did not take any medication for his sleep problems.

The main treatment goal for Harry was to reduce his sleep onset to no more than 30 minutes and to reduce the number of curtain calls he made.

Functional Behavioural Assessment. Results from the FBA indicated that the time at which Harry was instructed to go to bed was too early for both his chronological age and the time that he was being woken. As a result, Harry was in bed for approximately 11 hours. This compares to the 8-10 hours that would be expected for a person of Harry's age (Hirshkowitz et al., 2015). It was hypothesized that Harry was not experiencing sufficient biological sleep pressure to enable him to fall asleep at his bedtime of 9.00pm. As a result, Harry was spending a lot of time awake in his bedroom. Harry's residential house manager stated that due to its small size, it was common for Harry's room to get very hot. It was also reported that Harry was sensitive to over-heating. Therefore, it is likely that Harry found the extended periods of time he was spending awake in his bedroom at night uncomfortable. Based upon this information, it was assumed that Harry's constant curtain calls functioned to allow him to escape from the bedroom environment. The FBA also suggested that the automatic reinforcement that arose from the stereotypic behaviour Harry engaged in might also be maintaining his sleep-interfering behaviour. Thus, it was assumed that the primary functions of Harry's sleep disturbance were sensory.

Intervention. The first phase of treatment was designed to address Harry's significant sleep onset delay. This included faded bedtime and tying up Harry's hair before bed. These strategies were chosen as they targeted both circadian and antecedent factors.

Faded bedtime. Harry's bedtime was moved from 9.00pm to 10.30pm. This time was selected as it was more appropriate for his age and scheduled wake-time, and was much

closer to the time when he was actually falling asleep. Staff members were asked to avoid instructing Harry to go to bed until this time. In addition, Harry was woken consistently at 7.00am each morning. Staff members were asked to keep this bedtime consistent throughout both week and weekend nights.

Hair tying. As Harry's hair appeared to bother him, staff were asked to tie his hair in a bun before bedtime to ensure it was out of his face.

Intervention Phase Two. On day 30 the decision was made to introduce evening walks and a reward for compliance with the bedtime routine. These strategies were developed in collaboration with Harry's new house manager, who took over the role on day 20.

Evening walks. Harry's new house manager suggested that a walk in the evening would be beneficial in helping Harry settle at night. Staff members were asked to take Harry for a walk at the same time each evening in order to provide him with an age-appropriate activity to engage in during the lead up to bedtime.

Reward for bedtime compliance. During the first phase of treatment, staff reported a number of nights in which Harry did not comply with the instruction to go to bed. To address this non-compliance, staff members were asked to give Harry a reward if he followed their instruction to go to bed.

William.

Presenting Concerns. William was a 12-year-old boy who presented with early morning wakings and sleep-onset delay. William was put to bed at 7.30pm, and would take between 60 to 90 minutes to fall asleep, with sleep onset typically occurring between 8.00pm and 8.30pm. In this time, William tended to stay in his bedroom and either lie in bed or play quietly. Occasionally, William would call out for the attention of staff members. The house manager reported that William would wake anywhere between 1.00am and 6.00am. If

William woke in the early hours of the morning, he was rarely able to fall back asleep, and instead remained awake until it was time for him to get up for the day. In between the time when William woke and the time when he was supposed to wake up in the morning (approximately 6.30am), staff members provided him with quiet activities such as books to avoid waking other children. Staff members would supervise William during this time, but remain outside the room and engage with him as little as possible. The house manager also reported that William would wet the bed approximately three times a week.

William's sleep problems had been present since toddlerhood, but had improved since his arrival at the facility three years ago. For example, prior to his arrival, William would make lots of noise, cry and damage property at night. He also had very little awareness of day and night. The house manager believed that William's behaviour had improved as a direct result of the consistent bedtime routine that had been put in place for him at the facility (e.g. bath, dinner, jobs, activity with rest of children in the house, then bed). Despite this improvement William's house manager noted that he would revert back to sleeping only two to three hours a night whenever he became unwell (which typically occurred every five to six weeks).

In addition to a consistent bedtime routine, staff members also played music or lullabies just outside of William's bedroom in order to help William fall asleep. Once William fell asleep the music would be switched off. On the occasional night where William would appear distressed at bedtime, staff members would respond by sitting outside his bedroom until he fell asleep. William was also prescribed melatonin to help his sleep.

The house manager's treatment goals for William were: a) To reduce his sleep onset delay to no more than 30 minutes and b) to reduce his early wakings by helping him to remain asleep in his own bed until 6.00am.

Functional Behavioural Assessment. The FBA of William's sleep disturbance indicated that his early bedtime was contributing toward his elevated sleep onset and frequent early morning wakings. Research suggests that children of William's age require approximately 9-11 hours of sleep each night (Hirshkowitz et al., 2015). William was spending approximately 11 hours in his bedroom between the time he was bid goodnight, and when it was time for him to wake up in the morning. It was therefore hypothesized that William woke early in the morning either because he had experienced a sufficient amount of sleep, or because he did not have sufficient biological sleep pressure to maintain sleep for 11 hours. It is also likely that William experienced insufficient sleep pressure to fall asleep at his initial bedtime of 7.30pm, as this is particularly early for a child of his age.

Findings from the FBA suggested that a function of William's sleep onset delay and early morning wakings was to gain access to tangible preferred items such as toys and books as he was allowed to play quietly in his room during these times. Furthermore, as a member of staff would watch over William while he played, it is also possible that his sleep-interfering behaviours were being reinforced by adult attention. Thus, it was hypothesized that William's sleep disturbance was being maintained by a sleep-routine that did not align with his circadian rhythm, as well as social attention and access to tangible items.

Intervention. William's treatment plan included faded bedtime, a Gro-clock and reinforcement. These treatment strategies were chosen to address circadian and antecedent factors that may have been contributing to William's sleep onset delay and early morning waking.

Faded Bedtime. William's bedtime was pushed back one hour, to 8.30pm. This time was chosen as it was within 15 minutes of the time that William typically fell asleep and was a more appropriate bedtime for his age. Staff members were asked to allow William to

engage in activities that were conducive to sleep (such as reading a book) prior to this time. A consistent wake-time was also implemented, with staff members asked to ensure William was woken at 6.00am each morning.

Gro Clock. A GroClock is an electronic clock that changes face from a star to a sun to indicate when it is time to wake up in the morning. A GroClock was used to help William understand when he was allowed to get up in the morning. The clock was set so that the sun was depicted at 6.00am.

Steven.

Presenting concerns. Steven was an 11-year-old boy who presented with sleep onset delay and frequent curtain calls. Steven was put to bed between 7.30pm and 8.00pm. However he did not fall asleep until approximately 10.00 - 10.30pm. Thus, Steven's average sleep onset delay was between two and two-and-a-half hours. Once bid goodnight, Steven would repeatedly get out of bed. Once out of bed, Steven would make requests such as asking for food, asking to go to the toilet, or would walk out into the lounge or kitchen and lie on the floor. Approximately once a week, Steven would also engage in fecal smearing. In addition, Steven experienced anxiety around which staff member would be looking after him, and would therefore wait up to see who was working that night. On occasion, Steven would become upset at bedtime and cry. At such times, Steven would require the presence of a staff member in order to settle. Once asleep, Steven would typically sleep through the night without waking.

The house manager stated that Steven had displayed these sleep problems for the past three years. In the past however, Steven would also damage his bed by urinating or defecating on it, or by ripping the bed sheets and mattress. Staff members had tried a number of strategies to target Steven's sleep problems, including removing all of his toys from the

bedroom at night, allowing him to take a family picture to bed, and having a staff member standing or sitting outside the room. In addition, if Steven became upset, a staff member would sometimes cuddle him to help him settle. However, the house manager also reported that at times, engaging with Steven when he was distressed could result in escalation of his behaviour. Therefore, they generally found it best to supervise Steven from afar until he calmed down. Prior to study commencement Steven had been prescribed Fluoxetine, which he took each morning.

The house manager's treatment goals for Steven were: a) To reduce sleep onset; and b) to reduce the frequency of Steven's curtain calls.

Functional Behavioural Assessment. As with the other participants, researchers believed that Steven's bedtime was contributing to his sleep problems. First, it appeared that Steven was not experiencing sufficient sleep pressure to fall asleep within a reasonable time after going to bed. It is likely that this was due to his bedtime being developmentally inappropriate for Steven's age. At 11 years of age, it is appropriate for Steven to sleep for 9-11 hours a night (Hirshkowitz et al., 2015). However, Steven was spending approximately 12 hours in bed. Furthermore, Steven's house manager reported that Steven experienced anxiety about which staff member would be looking after him each night. As the shift change occurred at 9.00pm, after Steven's bedtime, it is likely that his level of arousal was heightened in anticipation of this change, making it harder for him to fall asleep. Results from the FBA also indicated that Steven's sleep interfering behaviours, such as crying and constant curtain calls, were being reinforced by the attention he received from staff members, including the comfort they sometimes provided. Therefore, it was hypothesized that the main function of Steven's sleep interfering behaviours was staff attention, while the bedtime set for him also contributed to his delayed sleep onset.

Intervention. To address Steven's sleep onset delay and frequent curtain calls, a treatment plan was designed that included faded bedtime, altering the time of staff-transitions, a Groclock and a visual schedule. These strategies were chosen because they addressed circadian and antecedent factors and were less restrictive than consequence-based strategies.

Faded Bedtime. Steven's bedtime was moved to 9.30pm, as this was closer to when he would typically fall asleep and a more appropriate bedtime for his age. This time was also chosen because it was after the staff transition period. Prior to this time, staff members were asked to allow Steven to engage in behaviours conducive to sleep (such as reading). These activities could take place either in Steven's room or in another area of the house, but not in bed. To keep Steven's wake time consistent, staff members were asked to wake him at 6.30am

Staff Transition. In an attempt to reduce the impact that the staff shift change had on Steven's ability to fall asleep, a member of the day staff team was rostered to stay on until Steven's new bedtime of 9.30pm.

Visual Schedule. Steven was provided with a visual schedule depicting the sequence of events that formed his bedtime routine. This included going to the toilet, brushing his teeth, circle time (a group discussion with the rest of the residents), reading, playing with his toys, and finally bedtime. This strategy was used to help Steven learn and follow each step in the bedtime routine.

Groclock. A Groclock was placed in Steven's bedroom when he began preparing for bed. At 9.30pm staff would change the symbol showing on the clock to a star, to signal to Steven that it was now time to get into bed and go to sleep. For safety reasons, the Groclock was removed from the bedroom once Steven had fallen asleep. Staff members were asked to

place the Groclock back in the bedroom before Steven woke for the morning, and to ensure that the sun was showing at 6.30am, as a signal that it was time to get up.

Chapter 7

Study Two Results

This section presents data on participants sleep outcomes following behavioural interventions for the three participants included in Study Two. The research team did not receive any intervention data for one participant. Therefore, only assessment and baseline data can be presented for this participant.

Quality of Data

For all three participants, there were a number of nights where the sleep diaries were incomplete (detailed below).

Harry. Harry was randomly assigned a five-night baseline phase. However due to the house manager being absent, this was extended two nights, resulting in Harry's baseline phase lasting for seven nights. Harry's treatment lasted for 49 days. Data for Harry's sleep onset delay was missing for day 17, 26, 39, and 52. On these days staff recorded that Harry refused to go to bed and instead slept on the couch. Five nights of curtain call data was also missing for Harry. This included day 48, 52, 56, 58 and 59.

William. William was randomly assigned a baseline period of 10 nights. William's treatment lasted 69 days. For reasons undisclosed to the researcher, sleep diaries were only partially completed on days 15, 21, 31, 41, 43, 57 and 64. Missing information was primarily related to sleep onset delay.

Steven. Steven was randomly assigned a 15-night baseline period. However the start of intervention was initially postponed due to home visits. It was then further postponed on three occasions for reasons that were not communicated to the research team. Later attempts to communicate with the house manager were not reciprocated. As a result, no intervention data is reported for Steven. After 36 days of baseline data, the researcher received no more

sleep diaries. Therefore, 7 days of assessment and 36 days of baseline data for William are presented.

Where possible, the behaviour scatterplots provided by staff were used to supplement missing sleep diary data. Behaviour scatterplots were based on 30-minute observations and showed when the child was first observed as being asleep, and what time they woke in the morning. This information was therefore able to supplement missing sleep onset delay data (provided that time put to bed was recorded) and early morning waking data. However, there were limitations to the use of the behaviour scatterplots. First, they could not compensate for missing curtain call data (relevant for Harry only). Second, they were recorded half hourly, which meant that estimations had to be made around the exact time that a child fell asleep or woke up. For example, if it was first recorded that the child was asleep between 9.30pm and 10.00pm, for the purposes of the current study it was recorded that sleep onset occurred at 9.30pm. Thus, SOD was only able to be detected within a range of 30 minutes. Lastly, the behaviour scatterplots began being recorded at 9.00pm, which was 30 minutes after William's bedtime (8.30pm). As a result, on the nights with missing SOD data for William, the minimum SOD that could be recorded was 30 minutes.

Effect of Intervention on Sleep Onset Delay

Figure 7 presents assessment, baseline and intervention data for sleep onset delay (SOD) (in minutes) for Harry and William. Assessment and baseline data is also presented for Steven.

Harry. During baseline, Harry's SOD was variable, but consistently high. The time it took him to fall asleep ranged from 90 – 240 minutes. During intervention, Harry's SOD remained variable, ranging from under five minutes to a maximum of 340 minutes (night 12 of intervention; night 26 overall). However, there was a slight decreasing trend in Harry's

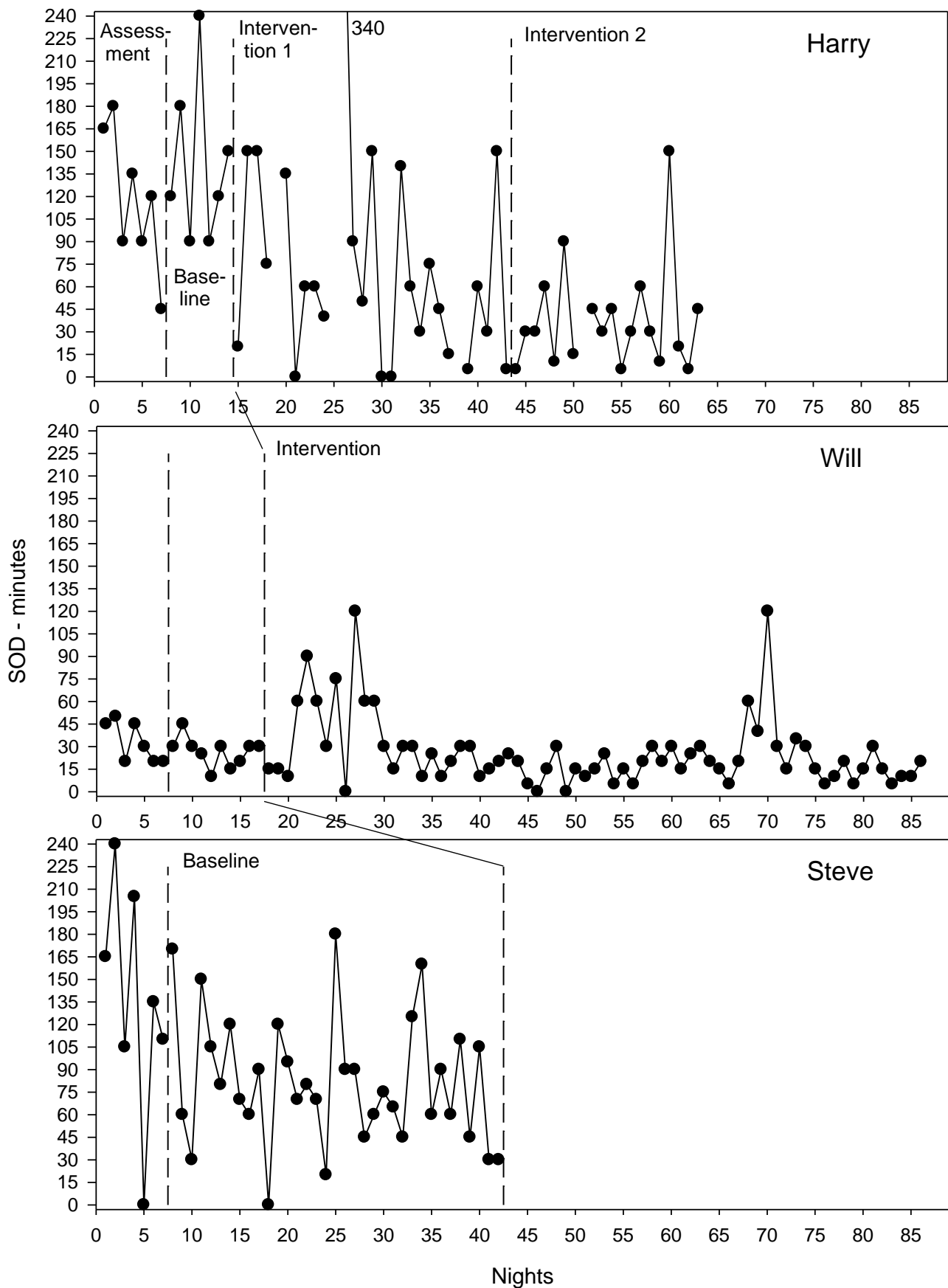


Figure 7. Duration of sleep onset delay (in minutes) during assessment, baseline and intervention for Study Two participants

SOD following intervention. This decrease in SOD is also reflected in the percentage of data points exceeding (or in this case below) the median (PEM). The median sleep onset delay for Harry during baseline was 120 minutes. Harry's SOD was below this for 37 out of the 45 data points recorded during the intervention phase, giving a PEM score of 0.82, or 82%. This score indicates that the intervention was moderately effective in reducing Harry's sleep onset delay.

William. During baseline, William's SOD was relatively stable, with a range of 15 to 45 minutes. In the two weeks following the implementation of the intervention, William's sleep onset increased and became more variable (with a range of 15 to 120 minutes). From day 13 of the intervention phase (day 30 overall) William's SOD stabilised slightly, and did not exceed 30 minutes until night 53 of intervention (night 70 overall), whereby it increased to 120 minutes. No explanation for this sudden spike in SOD was given. The PEM for William's sleep onset was 67%, with his sleep onset during intervention being below the baseline median of 30 minutes on 46 out of 69 nights. This suggests that it is the intervention was 'debatably effective' in reducing William's SOD.

Steven. During baseline, Steven's SOD was highly variable, ranging from zero to 180 minutes. The median SOD during this period was 75 minutes.

Effect of Intervention on Curtain Calls

Figure 8 presents assessment, baseline and intervention data relating to curtain calls for Harry and William, and assessment and baseline curtain call data for Steven.

Harry. During baseline, the frequency of curtain calls for Harry ranged between six and 14. Harry's curtain calls remained highly variable throughout phase one and phase two of intervention, ranging between zero and 15. Despite this, Harry's curtain calls did show a very slight downward trend during intervention phases compared with baseline data. The number

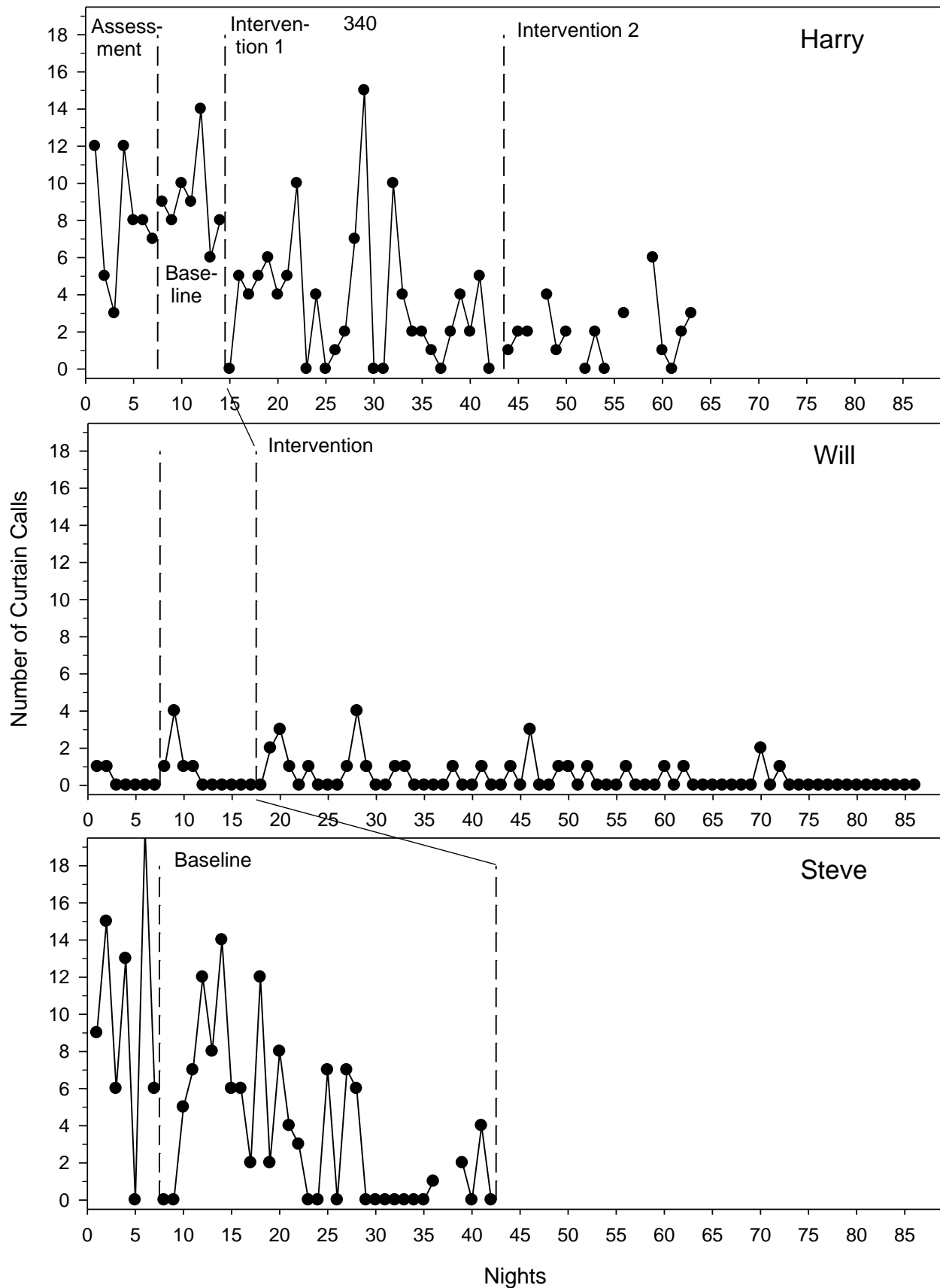


Figure 8. Frequency of curtain calls during assessment, baseline and intervention for Study Two participants.

of nights during intervention for which the number of curtain calls made was below the baseline median (9 curtain calls) was 41 out of 43 nights (excluding the nights for which data was missing). This produced a PEM score of 95%, which suggests that the intervention was highly effective in reducing Harry's curtain calls.

William. With the exception of one night where four curtain calls occurred, the frequency of curtain calls for William was consistently low during baseline for (ranging between zero and one). This pattern continued throughout the intervention phase. During intervention the maximum number of curtain calls made by William was four (night 28).

Steven. Two nights of curtain call data (night 37 and night 39) was missing for Steven during baseline. As with his SOD, Steven's curtain calls were highly variable during baseline. The number of curtain calls for Steven ranged from zero to 14. The median number of curtain calls made during baseline was relatively low, at two.

Effect of Intervention on Early Morning Waking

Figure 8 presents the data on early morning waking during assessment, baseline and intervention for William. Data is only presented for William, as early morning waking was not a sleep problem experienced by the other participants. During baseline, the number of minutes William woke before his goal wake time (6.00am) was extremely variable, ranging from zero to 120 minutes. As seen in Figure 8, William's early morning waking remained highly variable, also ranging between zero and 120 minutes. Despite this, there were some signs of improvement following intervention. For example, there were 31 mornings (out of 69) where William did not wake before six, and 52 nights where the number of minutes between when William woke and his goal wake time was less than the median baseline value (45 minutes). This produces a PEM score of 75%, indicating that the intervention was moderately effective in reducing William's early morning wakings.

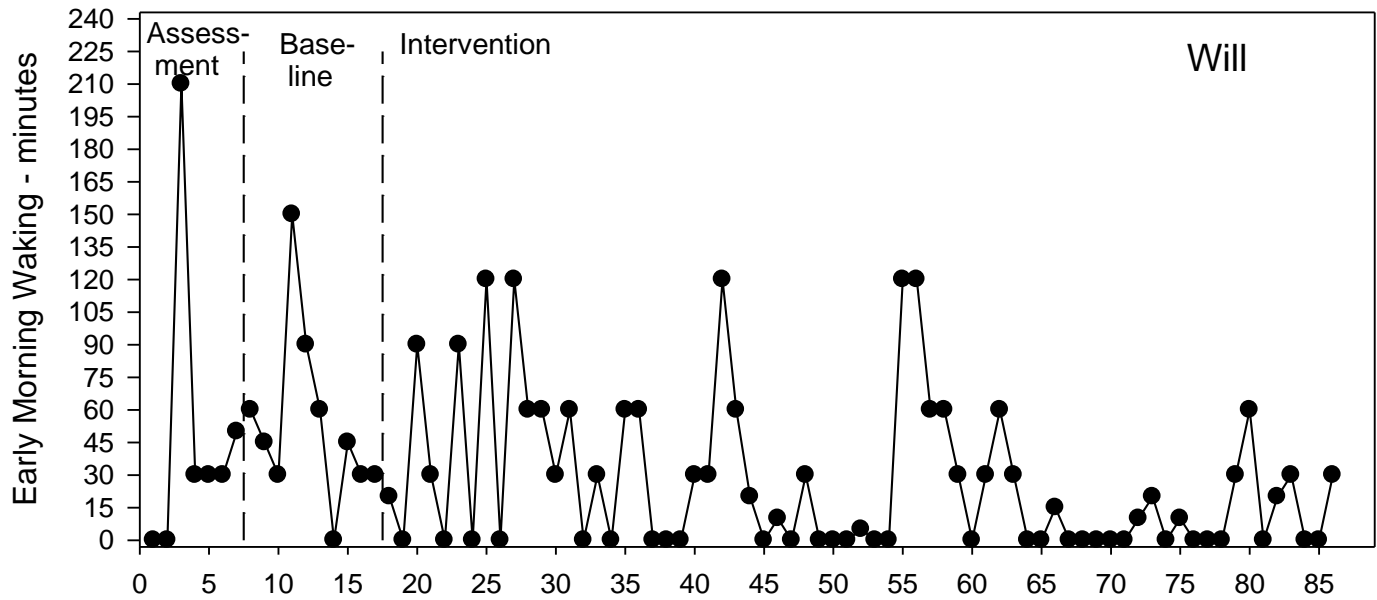


Figure 9. Duration of early morning waking (in minutes) during assessment, baseline and intervention for one of the Study Two participants.

Chapter 8

Study Two Discussion

The objective of Study Two was to evaluate the effectiveness staff delivered, FBA-informed behavioural sleep interventions implemented with children with developmental disabilities who are living in residential care. The key research question for this study was: *Are staff-implemented, FBA informed, behavioural interventions effective in treating sleep problems in three children with developmental disabilities and sleep problems who live in residential care?*

Within the current study, residential care staff implemented FBA-informed, behavioural interventions, with three school-aged children with ASD and a variety of sleep problems. Results indicate that these individualised sleep interventions delivered by staff were effective in reducing sleep onset delay and curtain calls for one of the two participants for whom this was targeted. Intervention was also effective in reducing early morning waking for one of these participants. Unfortunately, the effect of intervention could not be measured for the third participant, as no intervention data was provided.

This is one of the few studies to have evaluated the effectiveness of staff-implemented behavioural sleep interventions for children and adolescents with developmental disabilities who live in residential care. Only one other study was identified that examined the effectiveness of a staff-delivered behavioural intervention for sleep problems in this population (Hylkema & Vlaskamp, 2009). As with the current study, Hylkema and Vlaskamp (2009) also found evidence to support the effectiveness of staff-implemented behavioural interventions for sleep problems in children with developmental disabilities living in residential care. Positive outcomes observed by this earlier study include an increase in sleep efficiency and a reduction in sleep onset delay, thus aligning with findings from the current study. In addition, like the current study, Hylkema and Vlaskamp (2009) also found that

improvements in SOD were not consistent across all participants. The current study adds to emerging research in this field and provides further evidence to suggest that staff-administered behavioural interventions can be effective in reducing sleep problems among children with developmental disabilities residing out of home.

As the current study followed on from the educational workshop provided to staff in Study One, these findings also adds to literature evaluating the impact interventions that include a staff training for those working with children with developmental disabilities. This research suggests that staff training is an effective way to teach behavioural intervention techniques. These studies have found success with this approach, not only in the case of sleep interventions, but also in the treatment of social and communication deficits in children with developmental disabilities (Ingersoll et al., 2017; Kossyvaki et al., 2016; Weinkauff et al., 2011). Findings from the current study somewhat align with this research, in that staff training, followed by the provision of intervention support (such as individualized treatment plans) was effective in helping residential staff to implement behavioural sleep intervention programme in two out of three cases. This information should be considered when making decisions regarding the treatment of sleep (and other) problems in children and adolescents who live in residential facilities cared for by staff.

Findings from the current study also align with previous research investigating the effectiveness of parent-implemented, multimodal behavioural interventions for sleep problems in those with developmental disabilities, and in particular those that evaluate the use of faded bedtime. As the presenting sleep problems for both Harry (sleep onset delay), and William (sleep onset delay and early morning waking) had a strong circadian element, faded bedtime was the main component of both participants' intervention plans. The use of a faded bedtime procedure effectively reduced the SOD of one of two participants, and early morning waking in another. These findings align with previous research indicating that faded

bedtime is an effective component in the treatment of sleep initiation problems such as SOD and early morning waking in children and adolescents with developmental disabilities (Cooney et al., 2018; Delmere & Dounavi, 2017; Johnson et al., 2013; Papadopulus et al., 2015; Piazza & Fisher, 1991; Vriend et al., 2011).

In conjunction with the use of faded bedtime, the current study also employed additional behavioural strategies to treat participants' sleep problems, such as the use of reinforcement for Harry and a Groclock for William. As the treatments consisted of multiple components, it is unclear which components of intervention were essential to the effectiveness of treatment. However, findings do align with existing literature supporting the use of FBA-informed, multi-component sleep interventions for children with developmental disabilities (McLay, France, Knight, Blampied & Hastie, 2019; Weiskop et al., 2005; Reed et al., 2009; Vriend et al., 2011). The current study further extends this research to children and adolescents with developmental disabilities living in out of home care.

In spite of these positive findings, it is equally important to note the researcher did not receive clear confirmation regarding when, or if the treatment plan had in fact been implemented for the third participant. As such, the researcher does not know whether the approach would have been effective for this participant. In addition, the lack of implementation for one participant means that the current study was only successful in getting staff members on-board with the behavioural treatment approach in two out of three cases. This lack of consistency in staff response to the intervention limits what can be concluded about the format used for delivery.

A number of considerations were made in the design and delivery of the current study, to support staff implementing interventions, and to maintain the integrity of the treatment programmes. First, staff training and the relay of treatment plans were delivered to

staff in person, and in a group format. This was done to enable the researcher to build a rapport with staff, maximise staff engagement and also to increase the efficiency of the approach in regards to both time and cost. This form of delivery also gave staff an opportunity to ask any questions about the intervention process. Secondly, to help staff with the data collection process, the training workshop provided in Study One included instructions on how to complete the sleep diaries that were used for data collection in the current study. Thirdly, intervention plans were comprised mainly of antecedent based strategies, and extinction procedures were not used. These procedures were chosen primarily because they targeted the sleep problem but also due to the fact that they were relatively straightforward to implement and would not result in a post-extinction response burst. Lastly, the researcher attempted to provide additional intervention support by trying to maintain regular contact with each participant's house manager via phone and email while the intervention plans was being implemented.

Nevertheless, during the course of Study Two, researchers encountered a number of challenges that may have influenced the implementation of intervention plans, the measurement of treatment effects, and, indeed, the effectiveness the overall intervention approach. These variables may have contributed to the eventual withdrawal of one participant, and the lack of significant improvement in SOD observed in another. Challenges related to communication, data recording and staff turnover are discussed below.

Communication

It is general protocol among the wider research team for the researcher to have regular (initially, daily) contact with the families they are working with. This line of communication is extremely important as it means that the researcher has a consistent and clear understanding of the child's progress and allows for any problems with the intervention plan

to be promptly resolved. While the researcher attempted to remain in regular contact with the house managers for each participant, this level of communication was unable to be maintained for all participants. For example, regarding the participant that did complete the intervention, there were extended periods where communication between the researcher and house manager was lost. It is possible that this breakdown of communication was due to a lack of staff resources. The role of house managers is to supervise the running of the entire house, including all relevant staff and children. As a result, house managers have limited time available. Thus, it may be the case that even with the best of intentions, regular communication with the researcher was simply not possible for the individuals in these roles. These communication problems did, however, mean that the researcher often did not receive up-to-date information about participants' progress, or about the fidelity with which treatments were being implemented. As a result, the researchers were unable to make timely decisions in regards to treatment alterations or respond to difficulties that staff may have had in implementing the interventions appropriately.

The sporadic communication between the researcher and house managers also had implications for the timeline of the current research. Temporary breaks in communication meant that the participants began their interventions much later than anticipated. Initially, the study was designed to include a follow-up phase. However, these delays, in combination with the limited time frame of the current study, prevented follow-up investigation.

Staff Turnover

The second notable challenge associated with intervention implementation related to staff turnover. Over the course of the study, the house manager for one of the participants changed three times. Understandably, with each change in house manager it took a period of time for the person coming into the role to become familiar with the project and the specific

intervention plan for the child in their care. Therefore, the transition periods between house managers inevitably, and not unreasonably, resulted in further delays in relation to communication and the exchange of completed sleep diaries. As the first change of house manager occurred during the assessment phase, this also meant that the start of intervention for that particular child had to be postponed. In addition, the new house manager had not attended the staff training session provided as part of Study One. It is therefore possible that the new house manager's knowledge and attributions about sleep problems affected their ability to effectively oversee the implementation of interventions. While the researcher was not aware of any additional staff changes, it is likely that there was some turnover within the support staff working within each house. If new staff members did come on board during the intervention phase, then effective implementation of interventions relied on existing staff members correctly and effectively relaying information regarding participants' intervention plans and providing clear instructions on how and when to complete sleep diaries.

Recording of Data

Another notable challenge with implementation of the sleep interventions related to the recording of sleep diaries. It was not uncommon for sleep diaries to be returned to the researcher with missing information, which meant that the researcher had to supplement sleep diary data with information provided by the organisation's behaviour scatterplots. Given the staff-to-child ratio present in each house at night, it is possible that staff members may simply not have had sufficient time to complete the sleep diaries on top of their other responsibilities. For example, the staff member present in each house may have been attending to other children, and as a result were not able to accurately note down the exact time at which participant fell asleep. Furthermore, the staff member caring for each participant was not consistent. The fact that participants were cared for by a number of

different night staff may have hindered the consistent recording of data if this process was not appropriately communicated and shared between individuals.

Although the identification of these treatment barriers was not a key focus of the current study, it does align with previous research (Bach-Mortensen, Lange & Montgomery, 2018; Gray, Joy, Plath & Webb, 2013; James, Alemi & Zepeda, 2013; James, Thompson & Ringle, 2017). One of the most commonly reported barriers to the implementation of interventions within the setting of health and social welfare related organisations is a lack of staff resources, most notably, time (Bach-Mortensen et al., 2018; Gray et al., 2013; James et al., 2013). As indicated above, it is likely that limited staff resources also played a part in challenges experienced during the current study, such as difficulty maintain communication inconsistent recording of data. In addition, the current study's identification of staff turnover as a barrier to effective implementation aligns with previous research attempting to implement interventions within residential care settings (James et al., 2013; James et al., 2017). Alternatively, research suggests that high levels of intervention support, such as the continuous provision of training and feedback, and direct supervision by experts in the field facilitate effective implementation in these settings (Gray et al., 2013 James et al., 2017). The current study did provide intervention support in addition to staff training, such as the provision of individualized behavioural treatment plans informed by comprehensive assessment, and the availability of regular support from the researcher. However, in the current study the researcher was not present on-site while interventions were being implemented. It is therefore possible that the remote nature in which the support was provided to staff members implementing the interventions contributed to the observed outcomes. This possibility further highlights the importance of direct supervision when attempting to implemented interventions within these settings. More direct supervision would increase staff members' access to feedback and support during implementation, and help

ensure that both new and existing staff members understood the intervention process. Future research investigating staff-delivered interventions should also take into account the impact that staff resources have on their ability to not only implement the intervention, but to complete the tools used to measure treatment effects.

Limitations

There were four notable limitations to the current study. The first of these limitations is the low number of replications reported. For single case research designs, effect replication is a key mechanism in controlling threats to internal validity (Kratochwill et al., 2013). While the minimum number of replications required for single case research designs is not clearly stated, it is generally observed that at least three replications is required for validity (Kratochwill et al., 2013). The current study planned to measure treatment effects among three children, and was therefore originally designed to meet this criterion. However, for reasons outside their control, researchers did not receive intervention data for one of the participants. As a result, the validity of the findings reported by the current study is limited by insufficient replications.

Secondly, the current study relied solely on staff report measures, such as sleep diaries and behaviour scatterplots to measure changes in participants' sleep. This was necessary as alternative methods, such as actigraphs and video recording were not appropriate for the communal setting or would not have been tolerated by study participants. The reliance on staff-report measures limits the current study in two respects. First, it meant that data missing from sleep dairies could only be supplemented by information provided by staff-completed behaviour scatterplots. However, behaviour scatterplots did not include all the information required for the current study, such as the number of curtain calls made by children. Furthermore, behaviour scatterplots did not provide precise times at which

behaviours (e.g. falling sleep) occurred, as they were only recorded at half hour intervals. As a result of these factors, incomplete sleep diaries may have prevented clearer trends in behaviour following intervention from being observed. As there were a seven of nights where behaviour scatterplots were used to gauge William's sleep onset, it is possible that this might have contributed to the lack of consistent improvement in his SOD following treatment.

Secondly, the fact that the current study could not record video also meant that inter-observer agreement (IOA) could not be calculated. Researchers investigated alternative ways to assess IOA, such as having a second staff member complete sleep diaries for each child. However, as there was typically only one staff member present in each of the houses at night, this option was not possible. The absence of IOA data limits the current study as it may threaten the internal validity of its findings (Didden et al., 2002; Ledford & Gast, 2009; Watkins & Pacheco, 2000).

A third limitation of the current study is the absence of treatment fidelity data. As video recording was not able to be used in the current study, researchers cannot be certain that all aspects of the intervention plans were implemented as suggested. Incorrect, or incomplete implementation of interventions has been retrospectively identified as a reason for a lack of treatment effect observed by researchers who also attempted to investigate the impact of behavioural sleep interventions in children in a residential setting (Hylkema & Vlaskamp, 2009). Without evidence of treatment fidelity, it is impossible to identify whether the mixed findings recorded by the current study are in fact indicative of the effectiveness of treatment, or rather, caused by interventions not being administered correctly.

Lastly, the current study is limited by a lack of follow-up data. Follow-up data was not collected for participants due to time constraints. As a result, the current study cannot report whether the observed treatment effects were maintained, increased or lost over time.

Future Directions

Findings and limitations of the current study allude to four main recommendations for future research. First, a larger study examining the impact of staff-administered behavioural sleep interventions is warranted. The current study did not produce three treatment replications, which is a widely accepted criterion for validity (Kratochwill et al., 2013). Therefore, to be able to draw more valid conclusions regarding the effectiveness of this intervention approach, it is recommended that future research include a larger number of participants.

During the current study, it was observed that staff members struggled to maintain regular communication with the researcher and to complete sleep diaries consistently. It would be beneficial to know if factors related to the research procedures and training programme influenced this observation, as this could inform how similar studies might be modified in the future. One way to achieve this would be to obtain information regarding each staff member's experience of the intervention process. Therefore, a second recommendation is to extend future research in this area to include the assessment of treatment acceptability among the staff members involved in the intervention process.

A third recommendation for future research would be to expand the current study to include a wider range of participants. It is possible that the findings of the current study are limited to the sample population. It would therefore be beneficial to examine whether similar effects are observed among participants of varying gender, age, developmental disability, comorbidities and capabilities.

Lastly, it is possible that the treatment effects observed in the current study are not maintained long-term. To add to research regarding the effectiveness of the treatment approach employed by the current study, it is recommended that future research expand the study's time frame to include both short-term and long-term follow up phases.

Conclusion

The current study sought to evaluate the effectiveness of staff-delivered FBA-informed, behavioural interventions for sleep problems in three children with developmental disabilities living in residential care. In summary, findings indicate that with adequate training and intervention support staff can implement effective, individualized behavioural sleep interventions. Multimodal, staff delivered, behavioural treatments were effective in reducing SOD and curtain calls in one participant, and in reducing the occurrence and duration of early morning waking in another. However, observed improvements were not consistent across participants, and the effect of intervention could not be measured for one of the three participants. It is possible that challenges associated with implementing interventions in residential care settings, such as limited staff resources and staff turnover contributed to these inconsistent findings. While the current study's findings are promising, the low number of replications reported in this study limits the conclusions that can be drawn from them. Nevertheless, the current study demonstrates the promising effects of staff-delivered, FBA informed behavioural sleep interventions for children with developmental disabilities living in residential care.

Chapter 9

Overall Conclusion

This thesis builds upon existing research about behavioural interventions for sleep problems in children with developmental disabilities, by evaluating the effectiveness of a staff-focused intervention approach. The current study was comprised of two parts: Study one evaluated the impact of a staff-training workshop on the level of sleep knowledge held by staff members at a residential care facility for individual's with developmental disabilities. Staff member attributions about sleep problems were also assessed, including beliefs about the locus, stability and controllability of sleep problems in this population. Following on from this training, in Study Two researchers provided intervention support to help staff members administer individualized, FBA-informed, behavioural interventions to three children in their care. During Study Two, the effectiveness of these staff-delivered behavioural sleep interventions was assessed.

In conclusion, the current study found support for a staff-based approach to the treatment of sleep problems in children and adolescents with developmental disabilities and makes a number of important contributions to existing literature. The study indicates that group training is an effective and efficient way to increase residential staff members' knowledge of sleep problems and to introduce strategies commonly used in behavioural sleep interventions. Findings extend current research by associating this increase in knowledge with a simultaneous shift in attributions about the locus, stability and controllability of sleep problems in children with developmental disabilities. Following on from training, and with the intervention support provided by the research team, improvements were observed in the sleep behaviours of two out of the three children for which interventions were implemented. To date, children with developmental disabilities who live in residential care have been largely omitted from current literature relating to the treatment of sleep problems. The current

study makes an important contribution to the extremely limited existing evidence to support the use of behavioural interventions to treat sleep problems in this population. However, findings do suggest that in organizational settings, such as residential facilities, providing staff with a short training session and intervention support does not guarantee the effective implementation of behavioural sleep interventions. In these complex environments, an approach that provides a higher level of support and more direct supervision over an extended period of time may be required to produce consistent results. Without this level of support, it is possible that contextual factors, such as lack of staff resources and staff turnover may act as a barrier to effective treatment. While there is no simple solution, future research should endeavor to investigate ways in which the current study could be modified to overcome the challenges associated with these complex, yet extremely important environments, and evaluate the long-term impact of this intervention approach.

References

- Achenbach, T. M., & Rescorla, L. A. (2000). *Manual for the ASEBA Preschool forms and profiles*. Burlington: University of Vermont Department of Psychiatry.
- Alfano, C. A., Ginsburg, G. S., & Kingery, J. N. (2007). Sleep-related problems among children and adolescents with anxiety disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 46(2), 224-232.
doi:10.1097/01.chi.0000242233.06011.8e
- Alfano, C. A., Zakem, A. H., Costa, N. M., Taylor, L. K., & Weems, C. F. (2009). Sleep problems and their relation to cognitive factors, anxiety, and depressive symptoms in children and adolescents. *Depression and Anxiety*, 26(6), 503-512.
doi:10.1002/da.20443
- Allik, H., Larsson, J., & Smedje, H. (2006). Insomnia in school-age children with Asperger syndrome or high-functioning autism. *BMC Psychiatry*, 6(1), 18-18.
doi:10.1186/1471-244X-6-18
- Al-Yagon, M. (2015). Externalizing and internalizing behaviors among adolescents with learning disabilities: Contribution of adolescents' attachment to mothers and negative affect. *Journal of Child and Family Studies*, 24(5), 1343-1357.
doi:10.1007/s10826-014-9942-3
- American Academy of Sleep Medicine. (2005). The international classification of sleep disorders 2nd edition: Diagnostic and coding manual. *American Academy of Sleep Medicine*.
- Austin, K. L., Gordon, J. E., & O'Connell, A. (2013). Preliminary evaluation of Sleepwise program for children with sleep disturbance and developmental delay. *Child & Family Behavior Therapy*, 35(3), 195-211. doi:10.1080/07317107.2013.818886

- Bach-Mortensen, A. M., Lange, B. C. L., & Montgomery, P. (2018). Barriers and facilitators to implementing evidence-based interventions among third sector organisations: A systematic review. *Implementation Science: IS*, 13(1), 103-19. doi:10.1186/s13012-018-0789-7
- Bailey, T., Totsika, V., Hastings, R. P., Hatton, C., & Emerson, E. (2019). Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry*, 60(11), 1210-1218. doi:10.1111/jcpp.13080
- Bailly, D., Bailly-Lambin, I., Querleu, D., Beuscart, R., & Collinet, C. (2004). Sleep in adolescents and its disorders. A survey in schools. *L'Encephale*, 30(4), 352.
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal on Mental Retardation*, 107(6), 433-444.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4-5), 217-230. doi:10.1046/j.1365-2788.2003.00484.x
- Baker, B. L., Neece, C. L., Fenning, R. M., Crnic, K. A., & Blacher, J. (2010). Mental disorders in five-year-old children with or without developmental delay: Focus on ADHD. *Journal of Clinical Child & Adolescent Psychology*, 39(4), 492-505
doi:10.1080/15374416.2010.486321
- Baker, E. K., & Richdale, A. L. (2015). Sleep patterns in adults with a diagnosis of high-functioning autism spectrum disorder. *Sleep*, 38(11), 1765-1774.
doi:10.5665/sleep.5160

- Baker, E., Richdale, A., Short, M., & Gradisar, M. (2012). An investigation of sleep patterns in adolescents with high-functioning autism spectrum disorder compared with typically developing adolescents. *Developmental Neuropsychology*, 16(3), 155-165. doi:10.3109/17518423.2013.765518
- Bandino, M. L., Garfinkle, R. A., Zickefoose, B. A., & Hsieh, D. T. (2014). Epilepsy at a summer camp for children and young adults with developmental disabilities: A 3-year experience. *Military Medicine*, 179(1), 105-10. Retrieved from <http://search.proquest.com.ezproxy.canterbury.ac.nz/docview/1495444437?accountid=14499>
- Bathory, E., & Tomopoulos, S. (2017). Sleep regulation, physiology and development, sleep duration and patterns, and sleep hygiene in infants, toddlers, and preschool-age children. *Current Problems in Pediatric and Adolescent Health Care*, 47(2), 29-42. doi:10.1016/j.cppeds.2016.12.001
- Bauminger, N., Solomon, M., & Rogers, S. J. (2010). Externalizing and internalizing behaviors in ASD. *Autism Research*, 3(3), 101-112. doi:10.1002/aur.131
- Bautista, M., Whittingham, K., Edwards, P., & Boyd, R. N. (2018). Psychometric properties of parent and child reported sleep assessment tools in children with cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology*, 60(2), 162-172. doi:10.1111/dmcn.13609
- Becker, S. P., Epstein, J. N., Tamm, L., Tilford, A. A., Tischner, C. M., Isaacson, P. A., . . . Beebe, D. W. (2019). Shortened sleep duration causes sleepiness, inattention, and oppositionality in adolescents with attention-deficit/hyperactivity disorder: Findings from a crossover sleep

- restriction/extension study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 58(4), 433-442. doi:10.1016/j.jaac.2018.09.439
- Becker, S. P., Langberg, J. M., & Evans, S. W. (2015). Sleep problems predict comorbid externalizing behaviors and depression in young adolescents with attention deficit/hyperactivity disorder. *European Child & Adolescent Psychiatry*, 24(8), 897-907. doi:10.1007/s00787-014-0636-6
- Berubè, R. L., & Achenbach, T. M. (2010). *Bibliography of published studies using the Achenbach System of Empirically Based Assessment: 2006 Edition*. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families. Available online at www.ASEBA.org
- Bessey, M., Coulombe, J. A., Smith, I. M., & Corkum, P. (2013). Assessing parental sleep attitudes and beliefs in typically developing children and children with ADHD and ASD. *Children's Health Care*, 42(2), 116-133. doi:10.1080/02739615.2013.766096
- Bishop, P. A., & Herron, R. L. (2015). Use and misuse of the Likert item responses and other ordinal measures. *International Journal of Exercise Science*, 8(3), 297. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4833473/pdf/ijes_08_03_297.pdf
- Drake, C., Nickel, C., Burduvali, E., Roth, T., Jefferson, C., & Pietro, B. (2003). The Pediatric Daytime Sleepiness Scale (PDSS): Sleep habits and school outcomes in middle-school children. *Sleep*, 26(4), 455. doi:10.1093/sleep/26.4.455
- Blampied, N. (2013). Functional behavioural analysis of sleep in infants and children. Wolfson, A. R., & Montgomery-Downs, H. E. (Eds.). (2013). *Oxford handbook of infant, child, and adolescent sleep and behavior* (pp.169-188). Retrieved from <https://ebookcentral.proquest.com>

- Blampied, N. M. (2017). Analyzing therapeutic change using modified brinley plots: History, construction, and interpretation. *Behavior Therapy*, 48(1), 115-127.
- Blampied, N. M., & France, K. G. (1993). A behavioral model of infant sleep disturbance. *Journal of Applied Behavior Analysis*, 26(4), 477-492.
doi:10.1901/jaba.1993.26-477
- Boban, S., Leonard, H., Wong, K., Wilson, A., & Downs, J. (2018). Sleep disturbances in Rett syndrome: Impact and management including use of sleep hygiene practices. *American Journal of Medical Genetics Part A*, 176(7), 1569-1577.
doi:10.1002/ajmg.a.38829
- Bornstein, M. H., & Hendricks, C. (2013). Screening for developmental disabilities in developing countries. *Social Science & Medicine*, 97, 307-315
doi:10.1016/j.socscimed.2012.09.049
- Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin- Allsopp, M., ... & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 127(6), 1034-1042.
- Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(2), 115-121. doi:10.1002/mrdd.1016
- Braun, K. V. N., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., ... & Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991–2010. *PloS one*, 10(4),
doi:10.1371/journal.pone.0124120

- Breau, L. M., & Camfield, C. S. (2011). Pain disrupts sleep in children and youth with intellectual and developmental disabilities. *Research in Developmental Disabilities, 32*(6), 2829-2840. doi:10.1016/j.ridd.2011.05.023
- Breau, L. M., Camfield, C., Symon, D. N., Bodfish, J. W., McKay, A., & Finley, G. A. (2003). Pain and self-injurious behaviour in neurologically impaired children. *Journal of Pediatrics, 142*(5), 498-503. doi:10.1016/j.ridd.2011.05.023
- Bruni, O., Ferri, R., Vittori, E., Novelli, L., Vignati, M., Porfirio, M. C., . . . Curatolo, P. (2007). Sleep architecture and NREM alterations in children and adolescents with Asperger syndrome. *Sleep, 30*(11), 1577-1585. doi:10.1093/sleep/30.11.1577
- Bruni, O., Ottaviano, S., Guidetti, V., Romoli, M., Innocenzi, M., Cortesi, F., & Giannotti, F. (1996). The sleep disturbance scale for children (SDSC). construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. *Journal of Sleep Research, 5*(4), 251.
- Burbacher, T. M., Grant, K. S., & Sackett, G. P. (Eds.). (2007). *Primate models of children's health and developmental disabilities*. Retrieved from <https://ebookcentral.proquest.com>
- Burke, R. V., Kuhn, B. R., & Peterson, J. L. (2004). Brief report: A "storybook" ending to children's bedtime problems-the use of a rewarding social story to reduce bedtime resistance and frequent night waking. *Journal of Pediatric Psychology, 29*(5), 389-396. doi:10.1093/jpepsy/jsh042
- Buyse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Research, 28*(2), 193-213. doi:10.1016/0165-1781(89)90047-4

- Cain, N., & Gradisar, M. (2010). Electronic media use and sleep in school-aged children and adolescents: A review. *Sleep Medicine, 11*(8), 735-742.
doi:10.1016/j.sleep.2010.02.006
- Cairney, J., Rigoli, D., & Piek, J. (2013). Developmental coordination disorder and internalizing problems in children: The environmental stress hypothesis elaborated. *Developmental Review, 33*(3), 224-238.
- Camerota, M., Propper, C. B., & Teti, D. M. (2019). Intrinsic and extrinsic factors predicting infant sleep: Moving beyond main effects. *Developmental Review, 53*, 100871.
doi:10.1016/j.dr.2019.100871
- Carotenuto, M., Esposito, M., Cortese, S., Laino, D., & Verrotti, A. (2016). Children with developmental dyslexia showed greater sleep disturbances than controls, including problems initiating and maintaining sleep. *Acta Paediatrica, 105*(9), 1079-1082. doi:10.1111/apa.13472
- Carskadon, M. A. (2001). *Adolescent sleep patterns: Biological, social, and psychological influences*. Cambridge University Press. doi:10.1017/CBO9780511499999
- Chen, C., Culhane, D. P., Metraux, S., Park, J. M., Venable, J. C., & Burnett, T. C. (2016). They're not all at home: Residential placements of early adolescents in special education. *Journal of Emotional and Behavioral Disorders, 24*(4), 247-256.
doi:10.1177/1063426615625603
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. 2nd: Hillsdale, NJ: Erlbaum.
- Cohen, L. L., Feinstein, A., Masuda, A., & Vowles, K. E. (2014). Single-case research design in pediatric psychology: Considerations regarding data analysis. *Journal of Pediatric Psychology, 39*(2), 124-137. doi:10.1093/jpepsy/jst065

- Cortesi, F., Giannotti, F., Ivanenko, A., & Johnson, K. (2010). Sleep in children with autistic spectrum disorder. *Sleep Medicine, 11*(7), 659-664. doi:10.1016/j.sleep.2010.01.010
- Cortesi, F., Giannotti, F., & Ottaviano, S. (1999). Sleep problems and daytime behavior in childhood idiopathic epilepsy. *Epilepsia, 40*(11), 1557-1565. doi:10.1111/j.1528-1157.1999.tb02040.x
- Crowley, S. J., Acebo, C., & Carskadon, M. A. (2007). Sleep, circadian rhythms, and delayed phase in adolescence. *Sleep Medicine, 8*(6), 602-612. doi:10.1016/j.sleep.2006.12.002
- Crowley, S. J., Eliza, V. R., LeBourgeois, M. K., Acebo, C., Tarokh, L., Seifer, R., . . . Carskadon, M. A. (2014). A longitudinal assessment of sleep timing, circadian phase, and phase angle of entrainment across human adolescence. *PLoS One, 9*(11) doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1371/journal.pone.0112199
- Cunningham, C. E., Cremner, R., & Boyle, M. (1995). Large group community-based parenting programs for families of preschoolers at risk for disruptive behavior disorders: Utilization, cost effectiveness, and outcome. *Journal of Child Psychology and Psychiatry, 36* (7), 1141-1159. doi: 10.1111/j.1469-7610.1995.tb01362.x
- Cuomo, B. M., Vaz, S., Lee, E. A. L., Thompson, C., Rogerson, J. M., Falkmer, T. (2017). Effectiveness of Sleep-Based interventions for children with autism spectrum disorder: A Meta-Synthesis. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy, 37*(5), 555-578. doi:10.1002/phar.1920
- Danielsson, S., Gillberg, I. C., Billstedt, E., Gillberg, C., & Olsson, I. (2005). Epilepsy in young adults with autism: A prospective population-based follow-up study of 120 individuals diagnosed in childhood. *Epilepsia, 46*(6), 918-923. doi:10.1111/j.1528-1167.2005.57504.

- Dardennes, R. M., Al Anbar, N. N., Prado-Netto, A., Kaye, K., Contejean, Y., & Al Anbar, N. N. (2011). Treating the cause of illness rather than the symptoms: Parental causal beliefs and treatment choices in autism spectrum disorder. *Research in Developmental Disabilities*, 32, 1137–1146. Doi: <https://doi.org/10.1016/j.ridd.2011.01.010>
- de Bruin, E. J., van Kampen, R. K. A., van Kooten, T., & Meijer, A. M. (2014). Psychometric properties and clinical relevance of the adolescent sleep hygiene scale in Dutch adolescents. *Sleep Medicine*, 15(7), 789-797. doi:10.1016/j.sleep.2014.03.015
- Dekker, M. C., & Koot, H. M. (2003). DSM-IV disorders in children with borderline to moderate intellectual disability. II: Child and family predictors. *Journal of the American Academy of Child & Adolescent Psychiatry*, 42(8), 923-931. doi:10.1097/01.CHI.0000046891.27264.C1
- DeLeon, I. G., Fisher, W. W., & Marhefka, J. (2004). Decreasing self-injurious behavior associated with awakening in a child with autism and developmental delays. *Behavioral Interventions*, 19(2), 111-119. doi:10.1002/bin.154
- Deliens, G., Leproult, R., Schmitz, R., Destrebecqz, A., & Peigneux, P. (2015). Sleep disturbances in autism spectrum disorders. *Review Journal of Autism and Developmental Disorders*. doi:10.1007/s40489-015-0057-6
- Delemere, E., & Dounavi, K. (2018). Parent-implemented bedtime fading and positive routines for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 48(4), 1002-1019. doi:10.1007/s10803-017-3398-4
- DeVincent, C. J., Gadow, K. D., Delosh, D., & Geller, L. (2007). Sleep disturbance and its relation to DSM-IV psychiatric symptoms in preschool-age children with pervasive developmental disorder and community controls. *Journal of Child Neurology*, 22(2), 161-169. doi:10.1177/0883073807300310
- Didden, R., Curfs, L. M. G., van Driel, S., & de Moor, J. M. H. (2002). Sleep problems in

- children and young adults with developmental disabilities: Home-based functional assessment and treatment. *Journal of Behaviour Therapy and Experimental Psychiatry*, 33, 49-58.
- Didden, R., Korzilius, H., van Aperlo, B., van Overloop, C., & de Vries, M. (2002). Sleep problems and daytime problem behaviours in children with intellectual disability. *Journal of Intellectual Disability Research*, 46(7), 537-547.
- Dodge, N. N., & Wilson, G. A. (2001). Melatonin for treatment of sleep disorders in children with developmental disabilities. *Journal of Child Neurology*, 16(8), 581-584. doi:10.1177/088307380101600808
- Doo, S., & Wing, Y. K. (2006). Sleep problems of children with pervasive developmental disorders: Correlation with parental stress. *Developmental Medicine and Child Neurology*, 48(8), 650-655. doi:10.1017/S001216220600137X
- Durand, V. M. (2002). Treating sleep terrors in children with autism. *Journal of Positive Behavior Interventions*, 4(2), 66-72. doi:10.1177/109830070200400201
- Durand, V. M., & Christodulu, K. V. (2004). Description of a sleep-restriction program to reduce bedtime disturbances and night waking. *Journal of Positive Behavior Interventions*, 6(2), 83-91. doi:10.1177/10983007040060020301
- El Rafihi-Ferreira, R., Lewis, K. M., McFayden, T., & Ollendick, T. H. (2019). Predictors of nighttime fears and sleep problems in young children. *Journal of Child and Family Studies*, 28(4), 941-949. doi:10.1007/s10826-019-01332-9
- El Rafihi-Ferreira, R., Pires, M. L. N., & de Mattos Silveiras, Edwiges Ferreira. (2019). Behavioral intervention for sleep problems in childhood: A brazilian randomized controlled trial. *Psicologia: Reflexão e Crítica*, 32(1), 1-13. doi:10.1186/s41155-019-0118-3

- Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 51-58. doi:10.1046/j.1365-2788.2003.00464.x
- Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: A bi-national perspective. *Journal of Child Psychology and Psychiatry*, 51(5), 583-593. doi:10.1111/j.1469-7610.2009.02179.x
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499. doi:10.1192/bjp.bp.107.038729
- Etherton, H., Blunden, S., & Hauck, Y. (2016). Discussion of extinction-based behavioral sleep interventions for young children and reasons why parents may find them difficult. *Journal of Clinical Sleep Medicine : JCSM : Official Publication of the American Academy of Sleep Medicine*, 12(11), 1535-1543. doi:10.5664/jcsm.6284
- Fombonne, E., Simmons, H., Ford, T., Meltzer, H., & Goodman, R. (2001). Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(7), 820-827. doi:10.1097/00004583-200107000-00017
- Fraccaro, R. L., Stelnicki, A. M., & Nordstokke, D. W. (2015). Test Review: Multidimensional Anxiety Scale for Children by J. S. March. *Canadian Journal of School Psychology*, 30(1), 70-77. <https://doi.org/10.1177/0829573514542924>
- France, K. G., & Blampied, N. M. (2005). Modifications of systematic ignoring in the management of infant sleep disturbance: Efficacy and infant distress. *Child & Family Behavior Therapy*, 27(1), 1-16. doi:10.1300/J019v27n01_01

- Friedman, S. L., & Kalichman, M. A. (2014). Out-of-home placement for children and adolescents with disabilities. *Pediatrics*, 134(4), 836-846.
doi: [10.1542/peds.2014-2279](https://doi.org/10.1542/peds.2014-2279)
- Gabriels, R. L., Cuccaro, M. L., Hill, D. E., Ivers, B. J., & Goldson, E. (2005). Repetitive behaviors in autism: Relationships with associated clinical features. *Research in developmental disabilities*, 26(2), 169-181. doi:10.1016/j.ridd.2004.05.003
- Gadow, K. D., DeVinent, C. J., Pomeroy, J., & Azizian, A. (2005). Comparison of DSM-IV symptoms in elementary school-age children with PDD versus clinic and community samples. *Autism*, 9(4), 392-415. doi:10.1177/1362361305056079
- Galland, B. C., & Mitchell, E. Helping children sleep. *Archives of Disease in Childhood*, 95(10), 850. doi:10.1136/hrt.2008.152736;10.1136/adc.2009.162974;
- Gilliam, J. E. (2016). Gilliam autism rating scale: 3rd edition. *WARS*.
- Goldman, S. E., Malow, B. A., Newman, K. D., Roof, E., & Dykens, E. M. (2009). Sleep patterns and daytime sleepiness in adolescents and young adults with Williams syndrome. *Journal of Intellectual Disability Research*, 53(2), 182-188.
doi:10.1111/j.1365-2788.2008.01140.x
- Goldman, S. E., Richdale, A. L., Clemons, T., & Malow, B. A. (2011). Parental sleep concerns in autism spectrum disorders: Variations from childhood to adolescence. *Journal of Autism and Developmental Disorders*, 42(4), 531-538.
doi:10.1007/s10803-011-1270-5
- Goldman, S. E., Surdyka, K., Cuevas, R., Adkins, K., Wang, L., & Malow, B. A. (2009). Defining the sleep phenotype in children with autism. *Developmental Neuropsychology*, 34(5), 560-573. doi:10.1080/87565640903133509

- Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(11), 1337-1345. doi:10.1097/00004583-200111000-00015
- Grahame, V., Brett, D., Dixon, L., McConachie, H., Lowry, J., Rodgers, J., Steen, N., & Le Couteur, L. (2015). Managing repetitive behaviours in young children with autism spectrum disorder (ASD): Pilot randomised controlled trial of a new parent group intervention. *Journal of Autism and Developmental Disorders* 45, 3168–3182 (2015). <https://doi-org.ezproxy.canterbury.ac.nz/10.1007/s10803-015-2474-x>
- Grandin, L. D., Alloy, L. B., & Abramson, L. Y. (2006). The social zeitgeber theory, circadian rhythms, and mood disorders: review and evaluation. *Clinical psychology review*, 26(6), 679-694. <https://doi.org/10.1016/j.cpr.2006.07.001>
- Gray, C. (1998). Social Stories and comic strip conversations with students with Asperger syndrome and high-functioning autism. In E. Schopler, G. B. Mesibov, & L. J. Kuncie (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 167–198). New York: Plenum.
- Gray, M., Joy, E., Plath, D., & Webb, S. A. (2013). Implementing Evidence-Based Practice: A Review of the Empirical Research Literature. *Research on Social Work Practice*, 23(2), 157–166. <https://doi.org/10.1177/1049731512467072>
- Green, S. A., Berkovits, L. D., & Baker, B. L. (2015). Symptoms and development of anxiety in children with or without intellectual disability. *Journal of Clinical Child & Adolescent Psychology*, 44(1), 137-144. doi:10.1080/15374416.2013.873979
- Green, J., Gilchrist, A., Burton, D., & Cox, A. (2000). Social and psychiatric functioning in adolescents with Asperger syndrome compared with conduct disorder. *Journal of Autism and Developmental Disorders*, 30(4), 279-293.

- Guénolé, F., Godbout, R., Nicolas, A., Franco, P., Claustrat, B., & Baleyte, J. (2011). Melatonin for disordered sleep in individuals with autism spectrum disorders: Systematic review and discussion. *Sleep Medicine Reviews, 15*(6), 379-387. doi:10.1016/j.smr.2011.02.001
- Hale, L., & Guan, S. (2014;2015;). Screen time and sleep among school-aged children and adolescents: A systematic literature review. *Sleep Medicine Reviews, 21*, 50-58. doi:10.1016/j.smr.2014.07.007
- Hanley, G. P., Jin, C. S., Vanselow, N. R., & Hanratty, L. A. (2014). Producing meaningful improvements in problem behavior of children with autism via synthesized analyses and treatments. *Journal of Applied Behavior Analysis, 47*(1), 16-36. doi:10.1002/jaba.106
- Hanson, M. D., & Chen, E. (2010). Daily stress, cortisol, and sleep: The moderating role of childhood psychosocial environments. *Health Psychology, 29*(4), 394-402. doi:10.1037/a0019879
- Hartley, S. L. , Schaidle, E. M. & Burnson, C. F. (2013). Parental attributions for the behavior problems of children and adolescents with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics, 34*(9), 651–660. doi: 10.1097/01.DBP.0000437725.39459.a0.
- Hawes, D. J., & Dadds, M. R. (2004). Australian data and psychometric properties of the strengths and difficulties questionnaire. *Australian and New Zealand Journal of Psychiatry, 38*(8), 644-651. doi:10.1111/j.1440-1614.2004.01427.x
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629-642. doi:10.1007/s10803-012-1604-y

- Hemmingsson, H., Stenhammar, A. M., & Paulsson, K. (2009). Sleep problems and the need for parental night-time attention in children with physical disabilities. *Child: Care, health and development*, 35(1), 89-95.
- Henderson, J. A., Barry, T. D., Bader, S. H., & Jordan, S. S. (2011). The relation among sleep, routines, and externalizing behavior in children with an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 5(2), 758-767.
doi:10.1016/j.rasd.2010.09.003
- Hense, S., Barba, G., Pohlabein, H., De Henauw, S., Marild, S., Molnar, D., . . . Sahlgrenska Academy. (2011). Factors that influence weekday sleep duration in european children. *Sleep*, 34(5), 633-639. doi:10.1093/sleep/34.5.633
- Heussler, H., Chan, P., Price, A. M. H., Waters, K., Davey, M. J., & Hiscock, H. (2012). Pharmacological and non-pharmacological management of sleep disturbance in children: An Australian paediatric research network survey. *Sleep Medicine*, 14(2), 189-194. doi:10.1016/j.sleep.2012.09.023
- Hewitt, K. (1985). Behavioural approaches to sleeplessness in children with severe learning difficulties. *British Journal of Learning Disabilities*, 13(3), 112-114.
- Hill, C. M., Evans, H. J., Elphick, H., Farquhar, M., Pickering, R. M., Kingshott, R., ... & Gavlak, J. C. (2016). Prevalence and predictors of obstructive sleep apnoea in young children with Down syndrome. *Sleep Medicine*, 27, 99-106.
- Hirshkowitz, M., Whiton, K., Albert, S. M., Alessi, C., Bruni, O., DonCarlos, L., . . . Ware, J. C. (2015). National Sleep Foundation's updated sleep duration recommendations: Final report. *Sleep Health*, 1(4), 233. doi:10.1016/j.sleh.2015.10.004
- Hodge, D., Carollo, T. M., Lewin, M., Hoffman, C. D., & Sweeney, D. P. (2014). Sleep patterns in children with and without autism spectrum disorders: Developmental

comparisons. *Research in Developmental Disabilities*, 35(7), 1631-1638.

doi:10.1016/j.ridd.2014.03.037

Hodge, D.R., & Gillespie, D. (2003). Phrase completions: An alternative to Likert scales.

Social Work Research, 27(1), 45-55. doi:10.1093/swr/27.1.45

Hoffman, C. D., Sweeney, D. P., Gilliam, J. E., Apodaca, D. D., Lopez-Wagner, M. C., &

Castillo, M. M. (2005). Sleep problems and symptomology in children with autism.

Focus on Autism and Other Developmental Disabilities, 20(4), 194-200.

doi:10.1177/10883576050200040101

Hoffman, C., D., Sweeney, D. P., Gilliam, J. E., & Lopez-Wagner, M. C. (2006). Sleep

problems in children with autism and in typically developing children. *Focus on*

Autism and Other Developmental Disabilities, 21(3), 146-152.

Hoffman, C. D., Sweeney, D. P., Lopez-Wagner, M. C., Hodge, D., Nam, C. Y., &

Botts, B. H. (2008). Children with autism: Sleep problems and mothers' stress.

Focus on Autism and Other Developmental Disabilities, 23(3), 155-165.

doi:10.1177/1088357608316271

Hollway, J. A., & Aman, M. G. (2011). Sleep correlates of pervasive developmental

disorders: A review of the literature. *Research in Developmental Disabilities*,

32(5), 1399-1421. <https://doi.org/10.1016/j.ridd.2011.04.001>

Hollway, J. A., Aman, M. G., & Butter, E. (2013). Correlates and risk markers for

sleep disturbance in participants of the autism treatment network. *Journal of*

Autism and Developmental Disorders, 43(12), 2830-2843. doi:10.1007/s10803-013-

1830-y

Hostyn, I., & Maes, B. (2007). Parents' perspectives on grounds for out-of-home placement

of young children with a disability. *The British Journal of Development Disabilities*,

53(105), 131-146. doi:10.1179/096979507799103423

- Howlin, P. (1984). A brief report on the elimination of long term sleeping problems in a 6-year-old autistic boy. *Behavioural and Cognitive Psychotherapy*, 12(3), 257-260.
- Hurl, K., Wightman, J., Haynes, S. N., & Virues-Ortega, J. (2016). Does a pre-intervention functional assessment increase intervention effectiveness? A meta-analysis of within-subject interrupted time-series studies. *Clinical Psychology Review*, 47, 71-84. doi:10.1016/j.cpr.2016.05.003
- Husky, M. M., Otten, R., Boyd, A., Pez, O., Bitfoi, A., Carta, M. G., . . . Kovess-Masfety, V. (2020). Psychometric properties of the strengths and difficulties questionnaire in children aged 5–12 years across seven european countries. *European Journal of Psychological Assessment*, 36(1), 65-76. doi:10.1027/1015-5759/a000489
- Hutchins, T. L., & Prelock, P. A. (2013). The social validity of Social Stories™ for supporting the behavioural and communicative functioning of children with autism spectrum disorder. *International Journal of Speech-Language Pathology*, 15(4), 383–395. <https://doi-org.ezproxy.canterbury.ac.nz/10.3109/17549507.2012.743174>
- Hylkema, T., Petitiaux, W., & Vlaskamp, C. (2011). Utility of staff training on correcting sleep problems in people with intellectual disabilities living in residential settings: Staff training on sleep problems. *Journal of Policy and Practice in Intellectual Disabilities*, 8(2), 85-91. doi:10.1111/j.1741-1130.2011.00294.x
- Hylkema, T., & Vlaskamp, C. (2009). Significant improvement in sleep in people with intellectual disabilities living in residential settings by non-pharmaceutical interventions. *Journal of Intellectual Disability Research*, 53(8), 695–703. doi:10.1111/j.1365-2788.2009.01177.x
- Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., . . . Magnusson, C. (2015). Changes in prevalence of autism spectrum disorders in

- 2001–2011: Findings from the stockholm youth cohort. *Journal of Autism and Developmental Disorders*, 45(6), 1766-1773. doi:10.1007/s10803-014-2336-y
- Ingersoll, B., Berger, N., Carlsen, D., & Hamlin, T. (2017). Improving social functioning and challenging behaviors in adolescents with ASD and significant ID: A randomized pilot feasibility trial of reciprocal imitation training in a residential setting. *Developmental Neurorehabilitation*, 20(4), 236-246. doi:10.1080/17518423.2016.1211187
- Ingram, K., Lewis-Palmer, T., & Sugai, G. (2005). Function-based intervention planning: Comparing the effectiveness of FBA function-based and non—function-based intervention plans. *Journal of Positive Behavior Interventions*, 7(4), 224-236. doi:10.1177/10983007050070040401
- Jakobsson, M., Josefsson, K., Jutengren, G., Sandsjö, L., Högberg, K. (2019). Sleep duration and sleeping difficulties among adolescents: Exploring associations with school stress, self-perception and technology use. *Scandinavian Journal of Caring Sciences*, 33(1), 197-206. doi:10.1111/scs.12621
- James, S., Alemi, Q., & Zepeda, V. (2013). Effectiveness and implementation of evidence-based practices in residential care settings. *Children and Youth Services Review*, 35(4), 642-656. doi:10.1016/j.chilyouth.2013.01.007
- James, S., Thompson, R. W., & Ringle, J. L. (2017). The Implementation of Evidence-Based Practices in Residential Care: Outcomes, Processes, and Barriers. *Journal of Emotional and Behavioral Disorders*, 25(1), 4–18. <https://doi.org/10.1177/1063426616687083>
- Jan, J. E., & Freeman, R. D. (2004). Melatonin therapy for circadian rhythm sleep disorders in children with multiple disabilities: What have we learned in the last

- decade? *Developmental Medicine and Child Neurology*, 46(11), 776-782.
doi:10.1017/S0012162204001331
- Jan, J. E., Owens, J. A., Weiss, M. D., Johnson, K. P., Wasdell, M. B., Freeman, R. D., & Ipsiroglu, O. S. (2008). Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics*, 122(6), 1343.
- Jin, C. S., Hanley, G. P., & Beaulieu, L. (2013). an individualized and comprehensive approach to treating sleep problems in young children. *Journal of Applied Behavior Analysis*, 46(1), 161-180. doi:10.1002/jaba.16
- Ji, X., & Liu, J. (2016). Subjective sleep measures for adolescents: A systematic review: Subjective sleep measures for adolescents. *Child: Care, Health and Development*, 42(6), 825-839. doi:10.1111/cch.12376
- Johnson, C. R., DeMand, A., Lecavalier, L., Smith, T., Aman, M., Foldes, E., & Scahill, L. (2016). Psychometric properties of the children's sleep habits questionnaire in children with autism spectrum disorder. *Sleep Medicine*, 20, 5-11.
doi:10.1016/j.sleep.2015.12.005
- Johnson, C. R., Turner, K. S., Foldes, E., Brooks, M. M., Kronk, R., & Wiggs, L. (2013). Behavioral parent training to address sleep disturbances in young children with autism spectrum disorder: A pilot trial. *Sleep Medicine*, 14(10), 995-1004.
doi:10.1016/j.sleep.2013.05.013
- Johnston, C., & Freeman, W. (1997). Attributions for child behaviour in parents of children without behaviour disorders and children with attention deficit-hyperactivity disorder. *Journal of Consulting and Clinical Psychology*, 65, 636-645. doi:10.1037/0022-006X.65.4.636
- Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., . . . Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum

disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders*, 40(11), 1361-1370. doi:10.1007/s10803-010-0996-9

Karkhaneh, M., Clark, B., Ospina, M. B., Seida, J. C., Smith, V., & Hartling, L. (2010).

Social StoriesTM to improve social skills in children with autism spectrum disorder: A systematic review. *Autism*, 14(6), 641–662.

<https://doi.org/10.1177/1362361310373057>

Kanis, J. B., Schwerdtle, B., Kübler, A., & Schlarb, A. A. (2015). Parent perceptions and practices regarding sleep in children: Results of a demographic survey in a nonclinical sample. *Somnologie - Schlafforschung Und Schlafmedizin*, 19(4), 263-270. doi:10.1007/s11818-015-0033-5

Karren, B. C. (2017). A test review: Gilliam, j. E. (2014). Gilliam autism rating scale–third edition (gars-3). *Journal of Psychoeducational Assessment*, 35(3), 342-346. doi:10.1177/0734282916635465

Keenan, R. A., Wild, M. R., McArthur, I., & Espie, C. A. (2006). Children with developmental disabilities and sleep problems: Parental beliefs and treatment acceptability. *Journal of Applied Research in Intellectual Disabilities*, 20(5), 455-465. doi:10.1111/j.1468-3148.2007.00382.x

Kelmanson, I. A. (2017). Sleep disturbances, behavioural problems and adaptive skills in children with Down's syndrome. *Early Child Development and Care*, 187(11), 1679-1693. doi:10.1080/03004430.2016.1180790

Kersten, P., Czuba, K., McPherson, K., Dudley, M., Elder, H., Tauroa, R., & Vandal, A. (2016). A systematic review of evidence for the psychometric properties of the strengths and difficulties questionnaire. *International Journal of Behavioral Development*, 40(1), 64-75. doi:10.1177/0165025415570647

- Khanna, A. K., Prabhakaran, A., Patel, P., Ganjiwale, J. D., & Nimbalkar, S. M. (2015). Social, psychological and financial burden on caregivers of children with chronic illness: A cross-sectional study. *The Indian Journal of Pediatrics*, 82(11), 1006-1011. doi:10.1007/s12098-015-1762-y
- Kokina, A., & Kern, L. (2010). Social story interventions for students with autism spectrum disorders: A meta-analysis. *Journal of Autism and Developmental Disorders*, 40(7), 812-26. doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1007/s10803-009-0931-0
- Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007). Risk factors for psychiatric disturbance in children with intellectual disability. *Journal of Intellectual Disability Research*, 51(1), 43-53. doi:10.1111/j.1365-2788.2006.00871.x
- Kossyvaki, L., Jones, G., & Guldberg, K. (2016). Training teaching staff to facilitate spontaneous communication in children with autism: Adult interactive style intervention (AIS). *Journal of Research in Special Educational Needs*, 16(3), 156-168. doi:10.1111/1471-3802.12068
- Krakowiak, P., Goodlin-Jones, B., Hertz-Picciotto, I., Croen, L. A., & Hansen, R. L. (2012). Sleep problems in children with autism spectrum disorders, developmental delays, and typical development: A population-based study. *Journal of Sleep Research*, 21(2), 231-231. doi:10.1111/j.1365-2869.2012.01012.x
- Kratochwill, T. R., Hitchcock, J. H., Horner, R. H., Levin, J. R., Odom, S. L., Rindskopf, D. M., & Shadish, W. R. (2013). Single-case intervention research design standards. *Remedial and Special Education*, 34(1), 26-38. doi:10.1177/0741932512452794
- Kuhn, B. R., & Weidinger, D. (2000). Interventions for infant and toddler sleep disturbance: A review. *Child & Family Behavior Therapy*, 22(2), 33-50. doi:10.1300/J019v22n02_03

- Kulman, G., Lissoni, P., Rovelli, F., Roselli, M. G., Brivio, F., & Sequeri, P. (2000). Evidence of pineal endocrine hypofunction in autistic children. *Neuro Endocrinology Letters*, 21(1), 31.
- Kuo, H., Muo, C., Chang, Y., & Lin, C. (2015). Change in prevalence status for children with developmental delay in Taiwan: A nationwide population-based retrospective study. *Neuropsychiatric Disease and Treatment*, 11, 1541. doi:10.2147/NDT.S84088
- Kuroda, H., Sawatari, H., Ando, S., Ohkusa, T., Rahmawati, A., Ono, J., . . . Chishaki, A. (2017). A nationwide, cross-sectional survey on unusual sleep postures and sleep-disordered breathing-related symptoms in people with down syndrome. *Journal of Intellectual Disability Research*, 61(7), 656-667. doi:10.1111/jir.12379
- Lambert, A., Tessier, S., Rochette, A., Scherzer, P., Mottron, L., & Godbout, R. (2016). Poor sleep affects daytime functioning in typically developing and autistic children not complaining of sleep problems: A questionnaire-based and polysomnographic study. *Research in Autism Spectrum Disorders*, 23, 94-106. doi:10.1016/j.rasd.2015.11.010
- Langberg, J. M., Molitor, S. J., Oddo, L. E., Eadeh, H.-M., Dvorsky, M. R., & Becker, S. P. (2020). Prevalence, patterns, and predictors of sleep problems and daytime sleepiness in young adolescents with ADHD. *Journal of Attention Disorders*, 24(4), 509–523. <https://doi.org/10.1177/1087054717690810>
- Lanigar, S., & Bandyopadhyay, S. (2017). Sleep and epilepsy: A complex interplay. *Missouri medicine*, 114(6), 453–457. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6139974/pdf/ms114_p0453.pdf
- LeBourgeois, M. K., Giannotti, F., Cortesi, F., Wolfson, A. R., & Harsh, J. (2005). The relationship between reported sleep quality and sleep hygiene in Italian and American adolescents. *Pediatrics*, 115, 257-265. Retrieved from <https://nyaspubs-onlinelibrary-wiley-com.ezproxy.canterbury.ac.nz/doi/pdf/10.1196/annals.1308.044>

- Lecuelle, F., Gustin, M., Leslie, W., Mindell, J. A., Franco, P., & Putois, B. (2020). French validation of the sleep disturbance scale for children (SDSC) in young children (aged 6 months to 4 years). *Sleep Medicine*, 67, 56-65. doi:10.1016/j.sleep.2019.09.014
- Ledford, J. R., & Gast, D. L. (2009). *Single subject research methodology in behavioral sciences*. New York: Routledge. doi:10.4324/9780203877937
- Lenz, A. S. (2013). Calculating effect size in single-case research: A comparison of nonoverlap methods. *Measurement and Evaluation in Counseling and Development*, 46(1), 64-73. doi:10.1177/0748175612456401
- Levin, A., & Scher, A. (2016). Sleep problems in young children with autism spectrum disorders: A study of parenting stress, mothers' Sleep-Related cognitions, and bedtime behaviors. *CNS Neuroscience & Therapeutics*, 22(11), 921-927. doi:10.1111/cns.12651
- Li, S., Arguelles, L., Jiang, F., Chen, W., Jin, X., Yan, C., . . . Shen, X. (2013). Sleep, school performance, and a school-based intervention among school-aged children: A sleep series study in china. *PloS One*, 8(7), e67928. doi:10.1371/journal.pone.0067928
- Lightfoot, E., Hill, K., & LaLiberte, T. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children and Youth Services Review*, 33(11), 2069-2075. doi:10.1016/j.childyouth.2011.02.019
- Limoges, E., Mottron, L., Bolduc, C., Berthiaume, C., & Godbout, R. (2005). Atypical sleep architecture and the autism phenotype. *Brain: A Journal of Neurology*, 128(5), 1049-1061. doi:10.1093/brain/awh425

- Lin, C., Muo, C., Chang, Y., & Kuo, H. (2015). Change in prevalence status for children with developmental delay in Taiwan: A nationwide population-based retrospective study. *Neuropsychiatric Disease and Treatment*, *11*, 1541-1547. doi:10.2147/NDT.S84088
- Lindly, O. J. , Chavez, A. E. & Zuckerman, K. E. (2016). Unmet health services needs among US children with developmental disabilities. *Journal of Developmental & Behavioral Pediatrics*, *37*(9), 712–723. doi: 10.1097/DBP.0000000000000363.
- Liu, X., Hubbard, J. A., Fabes, R. A., & Adam, J. B. (2006). Sleep disturbances and correlates of children with autism spectrum disorders. *Child Psychiatry and Human Development*, *37*(2), 179-91.
doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1007/s10578-006-0028-3
- Llewellyn, G., Dunn, P., Fante, M., Turnbull, L., & Grace, R. (1999). Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research*, *43*(3), 219-233. doi:10.1046/j.1365-2788.1999.00189.x
- Llewellyn, G., McConnell, D., Thompson, K., & Whybrow, S. (2005). Out-of-home placement of school-age children with disabilities and high support needs. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 1-6. doi:10.1111/j.1468-3148.2004.00201.x
- Loring, W. A., L. Johnston, R., Shui, A. M., & Malow, B. A. (2018). Impact of a brief behavioral intervention for insomnia on daytime behaviors in adolescents with autism spectrum disorders. *Journal of Contemporary Psychotherapy*, *48*(3), 165-177. doi:10.1007/s10879-018-9381-3
- Ma, H. (2006). An alternative method for quantitative synthesis of single-subject researchers: Percentage of data points exceeding the median. *Behavior Modification*, *30*, 598-617. doi:10.1177/0145445504272974

- Ma, H. (2009). The effectiveness of intervention on the behavior of individuals with autism: A meta-analysis using percentage of data points exceeding the median of baseline phase (PEM). *Behavior Modification*, 33, 339–359. doi:10.1177/0145445509333173.
- Mah, J. W. T., & Johnston, C. (2008). Parental social cognitions: Considerations in the acceptability of and engagement in behavioral parent training. *Clinical Child and Family Psychology Review*, 11(4), 218-236. doi:10.1007/s10567-008-0038-8
- Malow, B. A., Adkins, K. W., Reynolds, A., Weiss, S. K., Loh, A., Fawkes, D., Katz, T., Goldman, S. E., Madduri, N., Hundley, T., & Clemons, T. (2014). Parent- based sleep education for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44, 216-228.
- Malow, B. A., Marzec, M. L., McGrew, S. G., Wang, L., Henderson, L. M., & Stone, W. L. (2006). Characterizing sleep in children with autism spectrum disorders: A multidimensional approach. *Sleep*, 29(12), 1563-1571. doi:10.1093/sleep/29.12.1563
- Mannion, A., Leader, G., & Healy, O. (2013). An investigation of comorbid psychological disorders, sleep problems, gastrointestinal symptoms and epilepsy in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 7(1), 35-42. doi:10.1016/j.rasd.2012.05.002
- March, J. S. (2013). *Multidimensional Anxiety Scale for Children (2nd ed.)*. Toronto, Ontario, Canada: Multi-Health Systems.
- Martinez, J. R., Werch, B. L., & Conroy, M. A. (2016). School-based interventions targeting challenging behaviors exhibited by young children with autism spectrum disorder: A systematic literature review. *Education and Training in Autism and Developmental Disabilities*, 51(3), 265-280.

- Mash, E. J., & Wolfe, D. A. (2016). *Abnormal Child Psychology* (6th ed.). Boston, MA: Cengage Learning.
- Maskey, M., Warnell, F., Parr, J. R., Le Couteur, A., & McConachie, H. (2013). Emotional and behavioural problems in children with autism spectrum disorder. *Journal of autism and developmental d* • Matson, J. L., & Goldin, R. L. (2013).
- Matson, J. L., Dempsey, T., & Fodstad, J. C. (2009). Stereotypies and repetitive/restrictive behaviours in infants with autism and pervasive developmental disorder. *Developmental Neurorehabilitation*, 12(3), 122-127.
doi:10.1080/17518420902936730
- Matson, J. L., & Goldin, R. L. (2013). Comorbidity and autism: Trends, topics and future directions. *Research in Autism Spectrum Disorders*, 7(10), 1228-1233.
doi:10.1016/j.rasd.2013.07.003
- Matson, J. L., Wilkins, J., & Macken, J. (2008). The relationship of challenging behaviors to severity and symptoms of autism spectrum disorders. *Journal of Mental Health Research in Intellectual Disabilities*, 2(1), 29-44. doi:10.1080/19315860802611415
- Matthey, S., & Črnčec, R. (2012). Comparison of two strategies to improve infant sleep problems, and associated impacts on maternal experience, mood and infant emotional health: A single case replication design study. *Early Human Development*, 88(6), 437-442. doi:10.1016/j.earlhumdev.2011.10.010
- McDonagh, M. S., Holmes, R., & Hsu, F. (2019). Pharmacologic treatments for sleep disorders in children: A systematic review. *Journal of Child Neurology*, 34(5), 237-247. doi:10.1177/0883073818821030
- McDowall, P. S., Elder, D. E., & Campbell, A. J. (2017). Relationship between parent knowledge of child sleep, and child sleep practices and problems: A pilot study in a

- children's hospital cohort: Parent knowledge of child sleep. *Journal of Paediatrics and Child Health*, 53(8), 788-793. doi:10.1111/jpc.13542
- McDowall, P. S., Galland, B. C., Campbell, A. J., & Elder, D. E. (2017). Parent knowledge of children's sleep: A systematic review. *Sleep Medicine Reviews*, 31, 39-47. doi:10.1016/j.smrv.2016.01.002
- McGraw, K. O., & Wong, S. P. (1992). A common language effect size statistic. *Psychological Bulletin*, 111(2), 361–365. <https://doi.org/10.1037/0033-2909.111.2.361>
- McLay, L., France, K., Blampied, N., Danna, K., & Hunter, J. (2017). Using functional behavioral assessment to develop a multicomponent treatment for sleep problems in a 3-year-old boy with autism. *Clinical Case Studies*, 16(3), 254-270. doi:10.1177/1534650116688558
- McLay, L., France, K., Blampied, N., & Hunter, J. (2019). Using functional behavioral assessment to treat sleep problems in two children with autism and vocal stereotypy. *International Journal of Developmental Disabilities: Thematic Issue - Innovations in Psychological Interventions*, 65(3), 175-184. doi:10.1080/20473869.2017.1376411
- McLay, L. K., France, K. G., Knight, J., Blampied, N. M., & Hastie, B. (2019). The effectiveness of function-based interventions to treat sleep problems, including unwanted co-sleeping, in children with autism. *Behavioral Interventions*, 34(1), 30-51. doi:10.1002/bin.1651
- Melke, J., Goubran Botros, H., Chaste, P., Betancur, C., Nygren, G., Anckarsäter, H., . . . Bourgeron, T. (2008). Abnormal melatonin synthesis in autism spectrum disorders. *Molecular Psychiatry*, 13(1), 90-8. doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1038/sj.mp.4002016

- Meltzer, L. J. (2010). Clinical management of behavioral insomnia of childhood: Treatment of bedtime problems and night wakings in young children. *Behavioral Sleep Medicine*, 8(3), 172-189. doi:10.1080/15402002.2010.487464
- Meltzer, L. J. (2011). Factors associated with depressive symptoms in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 361-367.
- Meltzer, L. J., & Crabtree, V. M. (2015). *Pediatric sleep problems : A Clinician's guide to behavioral interventions*. Washington DC: American Psychological Association. doi:10.1037/14645-000
- Meltzer, L. J., & Mindell, J. A. (2007). Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: A pilot study. *Journal of Family Psychology*, 21, 67–73. doi: 10.1037/0893- 3200.21.1.67^[1]_{SEP}
- Meyer, J. A., Mundy, P. C., Van Hecke, A. V., & Durocher, J. S. (2006). Social attribution processes and comorbid psychiatric symptoms in children with Asperger syndrome. *Autism*, 10(4), 383-402. doi:10.1177/1362361306064435
- Miller, F. G., & Lee, D. L. (2013). Do Functional Behavioral Assessments improve intervention effectiveness for students diagnosed with ADHD? A single-subject meta-analysis. *Journal of Behavioral Education*, 22(3), 253-282. doi:10.1007/s10864-013-9174-4
- Millichap, J. G. (2006). Sleep disorders in children with epilepsy. *Pediatric Neurology Briefs*, 20(1), 3-3. doi:10.15844/pedneurbriefs-20-1-2
- Mindell, J. A., Kuhn, R., Lewin, D. S., Meltzer, L. J., & Sadeh, A. (2006). Behavioral treatment of bedtime problems and night wakings in infants and young children. *Sleep*, 29(10), 1263-1276.

- Mindell, J. A., Meltzer, L. J., Carskadon, M. A., & Chervin, R. D. (2008). Developmental aspects of sleep hygiene: Findings from the 2004 National Sleep Foundation sleep in America poll. *Sleep Medicine, 10*(7), 771-779. doi:10.1016/j.sleep.2008.07.016
- Ministry of Health. (2017). *Demographic report on clients allocated the Ministry of Health's disability support services as at September 2016*. Wellington: Ministry of Health.
- Mirfin-Veitch, B., Bray, A., & Ross, N. (2003). "It was the hardest and most painful decision of my life!": Seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *Journal of Intellectual & Developmental Disability, 28*(2), 99-111. doi:10.1080/1366825031000147049
- Montgomery, P., Stores, G., & Wiggs, L. (2004). The relative efficacy of two brief treatments for sleep problems in young learning disabled (mentally retarded) children: A randomised controlled trial. *Archives of Disease in Childhood, 89*, 125-130.
- Moon, E. C., Corkum, P., & Smith, I. M. (2010). Case study: A case-series evaluation of a behavioral sleep intervention for three children with autism and primary insomnia. *Journal of Pediatric Psychology, 36*(1), 47-54. doi:10.1093/jpepsy/jsq057
- Moore, M. (2012). Behavioral sleep problems in children and adolescents. *Journal of Clinical Psychology in Medical Settings, 19*(1), 77-83. doi:10.1007/s10880-011-9282-z
- Moore, P. S. (2004). The use of social stories in a psychology service for children with learning disabilities: A case study of a sleep problem. *British Journal of Learning Disabilities, 32*(3), 133-138. doi:10.1111/j.1468-3156.2004.00278.x
- Moss, A. H. B., Gordon, J. E., & O'Connell, A. (2014). Impact of Sleepwise: An intervention for youth with developmental disabilities and sleep disturbance. *Journal of Autism and Developmental Disorders, 44*(7), 1695-1707. doi:10.1007/s10803-014-2040-y

- Myers, S. M., Voigt, R. G., Colligan, R. C., Weaver, A. L., Storlie, C. B., Stoeckel, R. E., . . . Katusic, S. K. (2019). Autism spectrum disorder: Incidence and time trends over two decades in a population-based birth cohort. *Journal of Autism and Developmental Disorders*, 49(4), 1455-1474. doi:10.1007/s10803-018-3834-0
- Newman, C. J., O'Regan, M., & Hensey, O. (2006). Sleep disorders in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 48(7), 564-568. doi:10.1017/S0012162206001198
- Nicholas, B., Rudrasingham, V., Nash, S., Kirov, G., Owen, M. J., & Wimpory, D. C. (2007). Association of Per1 and Npas2 with autistic disorder: Support for the clock genes/social timing hypothesis. *Molecular Psychiatry*, 12(6), 581-92. doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1038/sj.mp.4001953
- Odom, S. L., Blacher, J. B., Horner, R. H., & Snell, M. E. (Eds.). (2007). *Handbook of developmental disabilities*. Retrieved from <https://ebookcentral.proquest.com>
- Oeseburg, B., Jansen, D. E. M. C., Dijkstra, G. J., Groothoff, J. W., & Reijneveld, S. A. (2010). Prevalence of chronic diseases in adolescents with intellectual disability. *Research in Developmental Disabilities*, 31(3), 698-704. <https://doi.org/10.1352/1934-9556-49.2.59>
- Olson, E. J., Boeve, B. F., & Silber, M. H. (2000). Rapid eye movement sleep behaviour disorder: Demographic, clinical and laboratory findings in 93 cases. *Brain: A Journal of Neurology*, 123(2), 331-339. doi:10.1093/brain/123.2.331
- Olusanya, B. O., Olusanya, J. O., Davis, A. C., Wertlieb, D., Boo, N., Nair, M. K. C., . . . Kassebaum, N. J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global

- burden of disease study 2016. *The Lancet Global Health*, 6(10), e1100-e1121.
doi:10.1016/S2214-109X(18)30309-7
- O'Reilly, M. F., Lancioni, G. E., & Sigafoos, J. (2004). Using paired-choice assessment to identify variables maintaining sleep problems in a child with severe disabilities. *Journal of Applied Behavior Analysis*, 37(2), 209-212. doi:10.1901/jaba.2004.37-209
- Owens, J. A., Jones, C., & Nash, R. (2011). Caregivers' knowledge, behavior, and attitudes regarding healthy sleep in young children. *Journal of Clinical Sleep Medicine*, 7(4), 345-350. doi:10.5664/JCSM.1186
- Owens, J. A., & Mindell, J. A. (2011). Pediatric insomnia. *Pediatric Clinics of North America*, 58(3), 555-569. doi:10.1016/j.pcl.2011.03.011
- Owens, J. A., & Moore, M. (2017). Insomnia in infants and young children. *PediatricAnnals*, 46(9), E321-E326. doi:10.3928/19382359-20170816-02
- Owens, J. A., Spirito, A., & McGuinn, M. (2000). The children's sleep habits questionnaire (CSHQ): Psychometric properties of a survey instrument for school-aged children. *Sleep*, 23(8), 1043-9. doi:10.1093/sleep/23.8.1d
- Owens, L. J., France, K. G., & Wiggs, L. (1999). Behavioural and cognitive-behavioural interventions for sleep disorders in infants and children: a review. *Sleep medicine reviews*, 3(4), 281-302.
- Øyane, N. M. F., & Bjorvatn, B. (2005). Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. *Autism*, 9(1), 83-94.
doi:10.1177/1362361305049031
- Paavonen, E. J., Porkka-Heiskanen, T., & Lahikainen, A. R. (2009). Sleep quality, duration and behavioral symptoms among 5-6-year-old children. *European Child & Adolescent Psychiatry*, 18(12), 747-754. doi:10.1007/s00787-009-0033-8

- Pandolfi, V., Magyar, C. I., & Dill, C. A. (2012). An initial psychometric evaluation of the CBCL 6–18 in a sample of youth with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 96-108. doi: [10.1016/j.rasd.2011.03.009](https://doi.org/10.1016/j.rasd.2011.03.009)
- Papadopoulos, N., Sciberras, E., Hisock, H., Mulraney, M., McGillivray, J., & Rinehart, N. (2015). The efficacy of a brief behavioral sleep intervention in school-aged children with ADHD and comorbid autism spectrum disorder. *Journal of Attention Disorders*, 1-10.
- Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. (2004). Economic implications of caregiving at midlife: Comparing parents with and without children who have developmental disabilities. *Mental Retardation*, 42(6), 413-426. doi:10.1352/0047-6765(2004)42<413:EIOCAM>2.0.CO;2
- Pfaller-Sadovsky, N., Arnott, G., & Hurtado-Parrado, C. (2019). Using principles from applied behaviour analysis to address an undesired behaviour: Functional analysis and treatment of jumping up in companion dogs. *Animal: An Open Access Journal from MDPI*, 9(12), 1091. doi:10.3390/ani9121091
- Phillips, L., & Appleton, R. E. (2004). Systematic review of melatonin treatment in children with neurodevelopmental disabilities and sleep impairment. *Developmental Medicine and Child Neurology*, 46(11), 771-5. Retrieved from <http://search.proquest.com.ezproxy.canterbury.ac.nz/docview/195589030?accountid=14499>
- Piazza, C. C., & Fisher, W. (1991). A faded bedtime with response cost protocol for treatment of multiple sleep problems in children. *Journal of Applied Behavior Analysis*, 24(1), 129-140. doi:10.1901/jaba.1991.24-129
- Piazza, C. C., Fisher, W. W., & Sherer, M. (1997). Treatment of multiple sleep problems in children with developmental disabilities: faded bedtime with response cost versus

bedtime scheduling. *Developmental medicine and child neurology*, 39(6), 414–418.

<https://doi.org/10.1111/j.1469-8749.1997.tb07456.x>

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2), 109–124. <https://doi.org.ezproxy.canterbury.ac.nz/10.1111/j.1365-2788.2006.00829.x>

Pornel, J. B., & Saldaña, G. A. (2013). Four common misuses of the Likert scale. *Philippine Journal of Social Sciences and Humanities University of the Philippines Visayas*, 18(2), 12-19. Retrieved from: https://www.researchgate.net/profile/Jonny_Pornel2/publication/309240449_Four_Common_Misuses_of_the_Likert_Scale/links/5806c75908ae03256b76fe0f.pdf

Qi, C. H., Barton, E. E., Collier, M., Lin, Y.-L., & Montoya, C. (2018). A systematic review of effects of social stories interventions for individuals with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, 33(1), 25–34. <https://doi.org/10.1177/1088357615613516>

Quach, J., Hiscock, H., & Wake, M. (2012). Sleep problems and mental health in primary school new entrants: Cross-sectional community-based study. *Journal of Paediatrics and Child Health*, 48(12), 1076-1081. doi:10.1111/j.1440- 1754.2012.02466.x

Quine, L. (2001). Sleep problems in primary school children: Comparison between mainstream and special school children. *Child: Care, Health and Development*, 27(3), 201-221. doi:10.1046/j.1365-2214.2001.00213.x

Reed, H. E., McGrew, S. G., Artibee, K., Surdkya, K., Goldman, S. E., Frank, K., . . . Malow, B. A. (2009). Parent-based sleep education workshops in autism. *Journal of Child Neurology*, 24(8), 936-945. doi:10.1177/0883073808331348

Richdale, A. L. (1999). Sleep problems in autism: Prevalence, cause, and intervention.

Developmental Medicine and Child Neurology, 41(1), 60-66.

doi:10.1017/S0012162299000122

Richdale, A. L. (2013). Autism and other developmental disabilities. In A. R. Wolfson, &

Montgomery - Down, H. E. (Ed.), *The Oxford Handbook of Infant, Child, and*

Adolescent Sleep and Behavior (pp. 471- 494). Oxford: Oxford University Press.

Richdale, A., Francis, A., Gavidia-Payne, S., & Cotton, S. (2000). Stress, behaviour, and

sleep problems in children with an intellectual disability. *Journal of Intellectual and*

Developmental Disability, 25(2), 147–161.

<https://doi.org/10.1080/13269780050033562>

Richdale, A. L., & Robinson, A. M. (2004). Sleep problems in children with an intellectual

disability: Parental perceptions of sleep problems, and views of treatment

effectiveness. *Child: Care, Health and Development*, 30(2), 139-150.

doi:10.1111/j.1365-2214.2004.00395.x

Richdale, A. L., & Schreck, K. A. (2009). Sleep problems in autism spectrum disorders:

Prevalence, nature, & possible biopsychosocial aetiologies. *Sleep Medicine Reviews*,

13, 403-411. <https://doi.org/10.1016/j.smr.2009.02.003>

Richdale, A., & Wiggs, L. (2005). Behavioral approaches to the treatment of sleep

problems in children with developmental disorders: What is the state of the art?

The International Journal of Behavioral Consultation and Therapy, 1(3), 165-190.

doi:10.1037/h0100743

Riley-Tillman, T. C., & Burns, M. K. (2009). *Evaluating educational interventions: Single-*

case design for measuring response to intervention. New York: Guilford Press.

- Sadeh, A. (1994). Assessment of intervention for infant night waking: Parental reports and activity-based home monitoring. *Journal of Consulting and Clinical Psychology*, 62(1), 63-68. doi:10.1037/0022-006X.62.1.63
- Sadeh, A., Gruber, R., & Raviv, A. (2002). Sleep, neurobehavioral functioning, and behavior problems in school-age children. *Child Development*, 73(2), 405-417.
doi:10.1111/1467-8624.00414
- Sadeh, A., Raviv, A., & Gruber, R. (2000). Sleep patterns and sleep disruptions in school-age children. *Developmental Psychology*, 36(3), 291-301. doi:10.1037/0012-1649.36.3.291
- Sajith, S. G., & Clarke, D. (2007). Melatonin and sleep disorders associated with intellectual disability: A clinical review. *Journal of Intellectual Disability Research*, 51(1), 2-13.
doi:10.1111/j.1365-2788.2006.00893.x
- Sanberg, S. A., Kuhn, B. R., & Kennedy, A. E. (2018). Outcomes of a behavioral intervention for sleep disturbances in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, , 1-28.
doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1007/s10803-018-3644-4
- Santrock, J. (2014). *Lifespan Development*. Australia, NSW: McGraw-Hill Education.
- Saulnier C. (2016). *Vineland Adaptive Behavior Scales, Third Edition* [Slides] [Online].
Available at: <http://downloads.pearsonclinical.com/videos/101816-vineland3/Vineland-3-Overview-Webinar-Handout-101816.pdf>. (retrieved 25 March 2020)
- Scattone, D., Wilczynski, S. M., Edwards, R. P., & Rabian, B. (2002). Decreasing disruptive behaviors of children with autism using social stories. *Journal of Autism and Developmental Disorders*, 32(6), 535-43.
doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1023/A:1021250813367

- Schlarb, A. A., Liddle, C. C., & Hautzinger, M. (2011). JuSt - a multimodal program for treatment of insomnia in adolescents: A pilot study. *Nature and Science of Sleep*, 3, 13. doi:10.2147/NSS.S14493
- Schreck, K., Mulick, J. A., & Smith, A. F. (2004). Sleep problems as possible predictors of intensified symptoms of autism. *Research in Developmental Disabilities*, 25(1), 57-66. doi:10.1016/j.ridd.2003.04.007
- Schreck, K. A., & Richdale, A. L. (2011). Knowledge of childhood sleep: A possible variable in under or misdiagnosis of childhood sleep problems. *Journal of Sleep Research*, 20(4), 589-597. doi:10.1111/j.1365-2869.2011.00922.x
- Schwichtenberg, A. J., Young, G. S., Hutman, T., Iosif, A. M., Sigman, M., Rogers, S. J., & Ozonoff, S. (2013). Behavior and sleep problems in children with a family history of autism. *Autism Research*, 6(3), 169-176. doi:10.1002/aur.1278
- Scruggs, T. E., & Mastropieri, M. A. (1998). Summarizing single-subject research: Issues and applications. *Behavior Modification*, 22(3), 221-242. doi:10.1177/01454455980223001
- Shea, N., Payne, E., & Russo, N. (2018). Brief report: Social functioning predicts externalizing problem behaviors in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(6), 2237-2242. doi:10.1007/s10803-017-3459-8
- Shokravi, F. A., Shooshtari, M. H., & Shahhatami, H. (2016). The impact of a sleep hygiene intervention on sleep habits in children with Attention Deficit/Hyperactivity disorder. *International Journal of Pediatrics*, 4(12), 4117-4126. doi:10.22038/ijp.2016.7285
- Schreck, K. A. (2001). Behavioral treatments for sleep problems in autism: Empirically supported or just universally accepted? *Behavioral Interventions*, 16(4), 265-278. doi:10.1002/bin.98

- Sikora, D. M., Johnson, K., Clemons, T., & Katz, T. (2012). The relationship between sleep problems and daytime behavior in children of different ages with autism spectrum disorders. *Pediatrics*, 130(Supplement 2), S83-S90.
- Sivertsen, B., Posserud, M., Gillberg, C., Lundervold, A. J., Hysing. (2012). Sleep problems in children with autism spectrum problems: A longitudinal population-based study. *Autism*, 16(2), 139-150. doi:10.1177/1362361311404255
- Simola, P., Niskakangas, M., Liukkonen, K., Virkkula, P., Pitkäranta, A., Kirjavainen, T., & Aronen, E. T. (2010). Sleep problems and daytime tiredness in Finnish preschool-aged children-a community survey. *Child: Care, Health and Development*, 36(6), 805-811. doi:10.1111/j.1365-2214.2010.01112.x
- Simpson, R., Oyekan, A. A., Ehsan, Z., & Ingram, D. G. (2018). Obstructive sleep apnea in patients with Down syndrome: current perspectives. *Nature and Science of Sleep*, 10, 287-293.
- Singh, K., & Zimmerman, A. W. (2015). Sleep in autism spectrum disorder and attention deficit hyperactivity disorder. *Seminars in Pediatric Neurology*, 22, 113-125.
<https://doi.org/10.1016/j.spen.2015.03.006>
- Skinner, B. F. (1969). *Contingencies of Reinforcement*. New York: Meredith Corporation.
- Soke, G. N., Maenner, M. J., Christensen, D., Kurzius-Spencer, M., & Schieve, L. A. (2018). Prevalence of co-occurring medical and behavioral conditions/symptoms among 4- and 8-year-old children with autism spectrum disorder in selected areas of the United States in 2010. *Journal of Autism and Developmental Disorders*, 48 (8), 2663-2676. doi: 10.1007/s10803-018-3521-1
- Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum

disorders. *Journal of Autism and Developmental Disorders*, 42(1), 48-59.

doi:10.1007/s10803-011-1215-z

Somerville, H., Tzannes, G., Wood, J., Shun, A., Hill, C., Arrowsmith, F., ... & O'Loughlin, E. V. (2008). Gastrointestinal and nutritional problems in severe developmental disability. *Developmental Medicine & Child Neurology*, 50(9), 712-716.

Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2016). *Vineland Adaptive Behavior Scales, Third Edition (Vineland-3)*. SanAntonio, TX, Pearson

Spindler, U. P., Hotopp, L. C., Bach, V. A., Hornemann, F., Syrbe, S., Andreas, A., . . . Bertsche, A. (2017). Seizure disorders and developmental disorders: Impact on life of affected families—a structured interview. *European Journal of Pediatrics*, 176(8), 1121-1129. doi:10.1007/s00431-017-2958-0

Spruyt, K., & Gozal, D. (2011). Sleep disturbances in children with attention-deficit/hyperactivity disorder. *Expert Review of Neurotherapeutics*, 11(4), 565-577. doi:10.1586/ern.11.7

Spruyt, K., O'Brien, L. M., Cluydts, R., Verleye, G. B., & Ferri, R. (2005). Odds, prevalence and predictors of sleep problems in school-age normal children. *Journal of sleep research*, 14(2), 163-176. doi:10.1111/j.1365-2869.2005.00458.x

Stores, G. (2016). Multifactorial influences, including comorbidities, contributing to sleep disturbance in children with a neurodevelopmental disorder. *CNS Neuroscience & Therapeutics*, 22(11), 875-879. doi:10.1111/cns.12574

Stores, G., & Stores, R. (2013). Sleep disorders and their clinical significance in children with Down syndrome. *Developmental Medicine & Child Neurology*, 55(2), 126-130. doi:10.1111/j.1469-8749.2012.04422.x

- Stores, R., & Stores, G. (2004). Evaluation of brief group-administered instruction for parents to prevent or minimize sleep problems in young children with Down Syndrome. *Journal of Applied Research in Intellectual Disabilities*, 17(2), 61-70.
doi:10.1111/j.1360-2322.2004.00174.x
- Storfer-Isser, A., Lebourgeois, M. K., Harsh, J., Tompsett, C. J., & Redline, S. (2013). Psychometric properties of the adolescent sleep hygiene scale. *Journal of Sleep Research*, 22(6), 707-716. doi:10.1111/jsr.12059
- Strange, J. F., Kenworthy, L., Daniolos, P., Case, L., Wills, M. C., Martin, A., & Wallace, G. L. (2012). Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Research in autism spectrum disorders*, 6(1), 406-412. doi:10.1016/j.rasd.2011.06.015
- Sutton, J. E., Huws, J. C., & Burton, C. R. (2019). Sleep hygiene education and children with developmental disabilities: Findings from a co-design study. *Journal of Intellectual Disabilities*. <https://doi.org/10.1177/1744629518818950>
- Tan, E., Healey, D., Gray, A. R., & Galland, B. C. (2012). Sleep hygiene intervention for youth aged 10 to 18 years with problematic sleep: A before-after pilot study. *BMC Pediatrics*, 12, 189. doi:http://dx.doi.org.ezproxy.canterbury.ac.nz/10.1186/1471-2431-12-189
- Taylor, M. A., Schreck, K. A., & Mulick, J. A. (2012). Sleep disruption as a correlate to cognitive and adaptive behavior problems in autism spectrum disorders. *Research in Developmental Disabilities*, 33(5), 1408-1417. doi:10.1016/j.ridd.2012.03.013
- Teng, A., Bartle, A., Sadeh, A., & Mindell, J. (2012). Infant and toddler sleep in Australia and New Zealand. *Journal of Paediatrics and Child Health*, 48(3), 268-273.
doi:10.1111/j.1440-1754.2011.02251.x

- Test, D. W., Richter, S., Knight, V., & Spooner, F. (2011). A comprehensive review and meta-analysis of the social stories literature. *Focus on Autism and Other Developmental Disabilities*, 26(1), 49-62. doi:10.1177/1088357609351573
- Tietze, A., Blankenburg, M., Hechler, T., Michel, E., Koh, M., Schlüter, B., & Zernikow, B. (2012). Sleep disturbances in children with multiple disabilities. *Sleep Medicine Reviews*, 16(2), 117-127. doi:10.1016/j.smrv.2011.03.006
- Thambirajah, M. S. (2011). *Developmental assessment of the school-aged child with developmental disabilities: A clinician's guide*. Retrieved from <https://ebookcentral.proquest.com>
- Thorpy, M. J. (2012). Classification of sleep disorders. *Neurotherapeutics*, 9(4), 687-701. doi:10.1007/s13311-012-0145-6
- Tordjman, S., Anderson, G. M., Pichard, N., Charbuy, H., & Touitou, Y. (2005). Nocturnal excretion of 6-sulphatoxymelatonin in children and adolescents with autistic disorder. *Biological Psychiatry*, 57(2), 134-138. doi:10.1016/j.biopsych.2004.11.003
- Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, 52(1), 91-99. doi:10.1111/j.1469-7610.2010.02295.x
- Turner, K. S., & Johnson, C. R. (2013). Behavioral interventions to address sleep disturbances in children with autism spectrum disorders: A review. *Topics in Early Childhood Special Education*, 33(3), 144-152. doi:10.1177/0271121412446204
- Van Naarden Braun, K., Christensen, D., Doernberg, N., Schieve, L., Rice, C., Wiggins, L., . . . Yeargin-Allsopp, M. (2015). Trends in the prevalence of autism spectrum disorder,

- cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan atlanta, 1991-2010. *PloS One*, 10(4).
doi:10.1371/journal.pone.0124120
- van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review*, 14(3), 302-317. doi:10.1007/s10567-011-0097-0
- van Steensel, F. J. A., & Heeman, E. J. (2017). Anxiety levels in children with autism spectrum disorder: A meta-analysis. *Journal of Child and Family Studies*, 26(7), 1753-1767. doi:10.1007/s10826-017-0687-7
- Varni, J. W., Burwinkle, T. M., Seid, M., & Skarr, D. (2003). The PedsQL™ 4.0 as a pediatric population health measure: Feasibility, reliability, and validity. *Ambulatory Pediatrics*, 3(6), 329-341. doi:10.1367/1539-4409(2003)003<0329:TPAAPP>2.0.CO;2
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the pediatric quality of life inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical Care*, 39(8), 800-812. doi:10.1097/00005650-200108000-00006
- Veatch, O. J., Sutcliffe, J. S., Warren, Z. E., Keenan, B. T., Potter, M. H., & Malow, B. A. (2017). Shorter sleep duration is associated with social impairment and comorbidities in ASD. *Autism Research*, 10(7), 1221-1238. doi:10.1002/aur.1765
- Vivian, J. (2018). *The effect of behavioural interventions for sleep problems on secondary outcomes in children with ASD and their parents* (Master's thesis, University of Canterbury, Christchurch, New Zealand). Retrieved from <https://ir.canterbury.ac.nz/bitstream/handle/10092/16531/Vivian%2c>

[%20Jemma_Master%27s%20Thesis.pdf?sequence=1&isAllowed=y](#)

- Vriend, J. L., Corkum, P. V., Moon, E. C., & Smith, I. M. (2011). Behavioral interventions for sleep problems in children with autism spectrum disorders: Current findings and future directions. *Journal of Pediatric Psychology*, 36(9), 1017-1029. doi:10.1093/jpepsy/jsr044
- Wade, C. M., Ortiz, C., & Gorman, B. S. (2007). Two-session group parent training for bedtime noncompliance in head start preschoolers. *Child & Family Behavior Therapy*, 29(3), 23-55. doi:10.1300/J019v29n03_03
- Watkins, M. W., & Pacheco, M. (2000). Interobserver agreement in behavioral research: Importance and calculation. *Journal of Behavioral Education*, 10(4), 205-212. doi:10.1023/A:1012295615144
- Weiner, B. (1980). *Human Motivation*. New York: Holt.
- Weiskop, S., Matthews, J., & Richdale, A. (2001). Treatment of sleep problems in a 5-year-old boy with autism using behavioural principles. *Autism*, 5(2), 209-221. doi:10.1177/1362361301005002009
- Weiskop, S., Richdale, A. L., & Mathews, J. (2005). Behavioural treatment to reduce sleep problems with autism and fragile x syndrome. *Developmental Medicine and Child Neurology*, 47(2), 94-104. doi:10.1017/s0012162205000186
- Weinkauff, S. M., Zeug, N. M., Anderson, C. T., & Ala'i-Rosales, S. (2011). Evaluating the effectiveness of a comprehensive staff training package for behavioral interventions for children with autism. *Research in Autism Spectrum Disorders*, 5(2), 864-871. doi:10.1016/j.rasd.2010.10.001
- Weiss, M. D., Wasdell, M. B., Bomben, M. M., Rea, K. J., & Freeman, R. D. (2006). Sleep hygiene and melatonin treatment for children and adolescents with ADHD and

- initial insomnia. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(5), 512-519. <https://doi.org/10.1097/01.chi.0000205706.78818.ef>
- Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2008). An exploration of parental attributions within the autism spectrum disorders population. *Behaviour Change*, 25(4), 201-214. doi:10.1375/bech.25.4.201
- Wiggs, L., & Stores, G. (1998). Behavioural treatment for sleep problems in children with severe learning disabilities and challenging daytime behaviour: Effect on sleep patterns of mother and child. *Journal of Sleep Research*, 7(2), 119-126. doi:10.1046/j.1365-2869.1998.00107.x
- Wilson, K. E., Miller, A. L., Bonuck, K., Lumeng, J. C., & Chervin, R. D. (2014). Evaluation of a sleep education program for low-income preschool children and their families. *Sleep*, 37(6), 1117-1125. doi:10.5665/sleep.3774
- Wolfson, A., Lacks, P., & Futterman, A. (1992). Effects of parent training on infant sleeping patterns, parents' stress, and perceived parental competence. *Journal of Consulting and Clinical Psychology*, 60(1), 41-48. doi:10.1037/0022-006X.60.1.41
- Woolfson, L. M., Taylor, R. J., & Mooney, L. (2011). Parental attributions of controllability as a moderator of the relationship between developmental disability and behaviour problems. *Child: Care, Health, and Development*, 37, 184-194. doi: <https://doi.org/10.1111/j.1365-2214.2010.01103.x>
- World Health Organization. (2011). *World report on disability 2011*. World Health Organization. Retrieved from https://www.who.int/disabilities/world_report/2011/report.pdf
- Xiong, N., Yang, L., Yu, Y., Hou, J., Li, J., Li, Y., . . . Jiao, Z. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in

China. *Research in Developmental Disabilities*, 32(1), 306-311.

doi:10.1016/j.ridd.2010.10.003

Zafeiriou, D. I., Kontopoulos, E. E., & Tsikoulas, I. (1999). Characteristics and prognosis of epilepsy in children with cerebral palsy. *Journal of Child Neurology*, 14(5), 289-294.

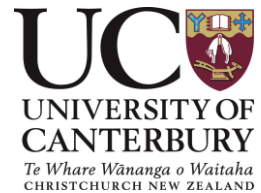
doi:10.1177/088307389901400504

Zisapel, N. (2018). New perspectives on the role of melatonin in human sleep, circadian rhythms and their regulation: Melatonin in human sleep and circadian rhythms. *British Journal of Pharmacology*, 175(16), 3190-3199. doi:10.1111/bph.14116

Appendix A

Board of Trustees and Residential Manager Information Sheet

College of Education, Health and Human Development
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Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disorders

Information for Board of Trustees and Residential Manager

Dear members of the Board of Trustees,

This research has been assessed and approved by the University of Canterbury Human Ethics Committee (HEC 2018/48).

We are a group of researchers at the University of Canterbury. Associate Professor Laurie McLay is a member of staff in the School of Health Sciences at the University of Canterbury. Laurie has many years experience in working with children and young people with developmental disabilities and their families. Associate Professor Karyn France has lectured here for many years, has conducted research into the treatment of paediatric sleep disturbance and is a registered clinical psychologist with considerable experience in this area. Professor Neville Blampied has a similar history of teaching and research. A number of Masters and PhD students and Child and Family Intern psychologists or registered psychologist also work on this project.

We would like you to consider allowing this research to be undertaken with staff and students at Hohepa Hawkes Bay. The primary purpose of this study is to investigate the effectiveness of treatments for sleep disturbance in children with developmental disabilities. Treatment can include a range of strategies, including both non-traditional approaches (such as white noise) and behavioural interventions. These approaches have been designed to minimise stress as much as possible for the staff and children using them. We are also interested in staff and children's experiences in using the treatments and any changes to children's lives, which result.

As a part of this study we would also like to investigate the experiences of residential support workers in implementing treatments for sleep disturbance, those treatments that they consider to be most acceptable, and the impact of successful treatment of sleep problems on child wellbeing, daytime behaviour, and quality of life. To do this, we will be asking residential support workers and the teacher of the child included in this study to complete some questionnaires about the well-being and behaviour of the children included in this study. These questionnaires will be administered at the commencement and conclusion of treatment and will collectively, take about one hour to complete.

Residential support workers who participate in this study will also be asked to participate in an initial interview to gather information about each child's sleep problems and daytime

behaviour. This initial meeting will last for approximately 1-1 ½ hours. We will then ask residential support workers to complete sleep diaries in which they will record further information about the child's sleep patterns each night. These diaries will be recorded each night throughout all phases of the study, as this will allow us to monitor the effectiveness of the treatment approach. The sleep diaries will take up to five minutes to complete each day. To help us gather further information about each child's sleep patterns, we will also ask them to wear a sleep watch or other activity-monitoring device. These watch-like devices record the movements associated with sleep and can be worn on the wrist or ankle, or secured into a pocket on the child's pyjamas. This method will allow us to measure sleep behaviour at times when an adult is not present.

When information about the child's sleep has been gathered, treatment will commence. Treatment may consist of a variety of strategies, which will be implemented by residential support workers with the support of the research team. We will maintain regular contact with these residential support workers during treatment. It is anticipated that children and residential support workers will be involved in the study over the course of a few months, but this will depend on the rate of the child's progress as well and staff members level of satisfaction with this progress.

For the purpose of this project, the research team will be working with residential support staff and house managers at Hohepa to conduct the necessary assessments and formulate interventions. Molly Mazey-Richardson, a research assistant/Masters/PhD student who also works as a part of our sleep team, may look at some of the information that we collect, such as sleep diary and sleep watch data. Please note that Molly Mazey-Richardson will be required to maintain the confidentiality of all data.

The staff, the school, and the children participating in this study will be assigned a code name to ensure anonymity and anything that participants in the study may say or do will be kept confidential. The results of the study may be submitted for publication to national or international journals and may also be presented at conferences. No identification of the child, family, school or home will be possible from any report, publication or presentation.

If you want to withdraw from the project before completion, you can do this at any time without penalty or repercussions.

Should you require any additional information about the study or if you would like to access the study findings you are able to do so at any stage. The data produced from this research will be kept in a locked cabinet at the University of Canterbury for a minimum of ten years.

If you agree to take part in the research, please sign the consent form that is attached.

If you have any complaints you may contact the Chair of the University of Canterbury Ethics Committee. The contact details are given below.

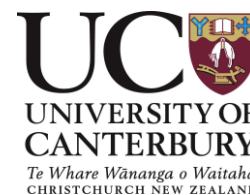
If you have any questions about this project please feel free to contact:

Associate Professor Laurie McLay
Phone: (03) 369-3522
Email: laurie.mclay@canterbury.ac.nz

Appendix B

Staff Member Information Sheet

College of Education, Health and Human Development
Phone: +64 027 740 6477
Email: laurie.mclay@canterbury.ac.nz
Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disorders

Information for Staff

This research has been assessed and approved by the University of Canterbury Human Ethics Committee (HEC 2018/48).

Dear residential support worker,

We are a group of researchers at the University of Canterbury. Associate Professor Laurie McLay is a member of staff in the School of Health Sciences at the University of Canterbury. Laurie has many years experience in working with children and young people with developmental disabilities and their families. Associate Professor Karyn France has lectured here for many years, has conducted research into the treatment of paediatric sleep disturbance and is a registered clinical psychologist with considerable clinical experience in this area. Professor Neville Blampied has a similar history of teaching and research. A number of Masters and PhD students and Child and Family Intern psychologists or registered psychologist also work on this project.

We would like you to consider participating in this research study. The primary purpose of this study is to investigate the effectiveness of treatments for sleep disturbance in children with developmental disabilities. Treatment can include a range of strategies, including both non-traditional approaches (such as white noise) and behavioural interventions. These approaches have been designed to minimise stress as much as possible for the staff and children using them. We are also interested in staff and children's experiences in using the treatments and any changes the children's lives, which result.

As a part of this study we would also like to investigate the experiences of residential support workers in implementing treatments for sleep disturbance, those treatments that they consider to be most acceptable, and the impact of successful treatment of sleep problems on child wellbeing, daytime behaviour, and quality of life. In order to do this we will be asking you and the teacher of the child included in this study to complete some questionnaires about the well-being and behaviour of the children included in this study. These questionnaires will be administered at both the commencement and conclusion of treatment. We may ask you to provide photos of some of the children going through the bedtime routine or at bedtime. These would be used in an individualized sleep story. If we do so, we will provide you with the opportunity to review and approve the social story and selected photographs.

If you agree to be a part of this study, we will Skype or phone you, to discuss the children who will be included in this study and to find out more about their sleep problems. This initial

meeting will last for approximately 1-1 ½ hours. We will then ask you to complete sleep diaries in which you will record further information about the child's sleep patterns each night. You will be asked to record sleep diaries each night throughout all phases of the study as this will allow us to monitor the effectiveness of the treatment approach. The sleep diaries will take up to five minutes to complete each night. When we have established an understanding of your child's sleep, we will work with you to develop sleep-related goals and treatment strategies. This will involve a treatment planning session with staff, which will last 1-1 ½ hours.

To help us gather further information about each child's sleep patterns, we will ask them to wear a sleep watch or other activity-monitoring device. These watch-like devices record the movements associated with sleep and can be worn on the wrist or ankle, or secured into a pocket on your child's pyjamas. This method will allow us to measure sleep behaviour at times when an adult is not present.

When information about the child's sleep has been gathered, treatment will commence. Treatment may consist of a variety of strategies, which you will implement with the support of the research team. We will provide you with all of the necessary information about each treatment approach and we will maintain regular contact with you during treatment. It is anticipated that you will be involved in the study over the course of a few months, but this will depend on the rate of the child's progress as well and your level of satisfaction with this progress.

For the purpose of this project, the research team will be working with you and other residential support staff to conduct the necessary assessments and formulate interventions. Molly Mazey-Richardson, a Masters student who also works as a part of our sleep team, may look at some of the information that we collect, such as sleep diary and actigraph data. Please note that Molly Mazey-Richardson will be required to maintain the confidentiality of all data.

You, the school, and the children participating in this study will be assigned a code name to ensure anonymity and anything that you or the child participating in the study says or does will be kept confidential. The results of the study may be submitted for publication to national or international journals and may also be presented at conferences. No identification of the child, family, school or home will be possible from any report, publication or presentation.

If you want to withdraw from the project before completion, you can do this at any time without penalty or repercussions.

Should you require any additional information about the study or if you would like to access the study findings you are able to do so at any stage. The data produced from this research will be kept in a locked cabinet at the University of Canterbury for a minimum of ten years.

If you have any complaints you may contact the Chair of the University of Canterbury Ethics Committee. The contact details are given below.

If you agree to take part in the research, please sign the consent form that is attached.

If you have any questions about this project please feel free to contact:

Associate Professor Laurie McLay will also be available to answer questions about this project:

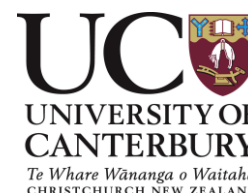
Phone (03) 369-3522

Email: laurie.mclay@canterbury.ac.nz

Appendix C

Parent/Caregiver Information Sheet

College of Education, Health and Human Development
Phone: +64 027 740 6477
Email: laurie.mclay@canterbury.ac.nz
Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disabilities

Information for Parents/Caregivers

This research has been assessed and approved by the University of Canterbury Human Ethics Committee (HEC 2018/48).

Dear Parent/ Caregiver,

We are a group of researchers at the University of Canterbury. Associate Professor Laurie McLay is a member of staff in the School of Health Sciences at the University of Canterbury. Laurie has many years experience in working with children and young people with developmental disabilities and their families. Associate Professor Karyn France has lectured here for many years, has conducted research into the treatment of paediatric sleep disturbance and is a registered clinical psychologist with considerable clinical experience in this area. Professor Neville Blampied has a similar history of teaching and research. A number of Masters and PhD students and registered Child and Family Intern psychologists or registered psychologists also work on this project.

We would like you and your child with a developmental disability to consider participating in this research study. The primary purpose of this study is to investigate the effectiveness of treatments for sleep disturbance in children with developmental disabilities. Treatment can include a range of strategies, including both non-traditional approaches (such as white noise) and behavioural interventions. These approaches have been designed to minimise stress as much as possible for the staff and children using them. We are also interested in staff and children's experiences in using the treatments and any changes to the children's lives, which result.

As a part of this study we would also like to investigate the experiences of staff in implementing treatments for sleep disturbance, those treatments that they consider to be most acceptable, and the impact of successful treatment of sleep problems on child wellbeing and quality of life. In order to do this we will ask staff to complete some questionnaires about your child's wellbeing and behaviour at the commencement and conclusion of treatment. We will do this either during visits to your home or via Skype.

If you agree to allow your child to be a part of this study, we will meet with you, or Skype you, to discuss your child's sleep behaviour and find out more about him/her and your family. This initial meeting will last for approximately 1-1 ½ hours.

To help us gather further information about your child's sleep patterns staff will complete daily sleep diaries in which they record information about your child's sleep patterns. In addition we may ask your child to wear an actigraph (sleep watch). This watch-like device records the movements associated with sleep and can be worn on the wrist or ankle, or secured into a pocket on your child's pyjamas. These methods will allow us to measure sleep behaviour at times when an adult is not present.

When information about your child's sleep behaviour has been gathered, treatment will commence. Staff will be offered a choice of treatment options, which they will then implement, with the support of the research team. Information about the treatment plan will be shared with you. If you are dissatisfied with the treatment approach or the degree of progress that is being made then you will be offered a choice of another treatment option. We will provide you with all of the necessary information about each treatment approach and we will maintain regular contact with you during treatment. It is anticipated that your involvement in the study will occur over the course of a few months, but will depend on the rate of your child's progress as well as staff satisfaction with the progress.

For the purpose of this project, myself, Laurie McLay (lead investigator) and a registered intern psychologist will be working closely with you to conduct the necessary assessments and formulate interventions. A Masters student, who also works as a part of our sleep team, may look at some of the information that we collect, such as actigraph data.

Your child will be assigned a code name to ensure anonymity and anything that you or your child says or does will be kept confidential. The results of the study may be submitted for publication to national or international journals and may also be presented at conferences. No identification of the child, staff, or family will be possible from any report, publication or presentation.

If you want to withdraw from the project before completion, you can do this at any time without penalty or repercussions.

Should you require any additional information about the study or if you would like to access the study findings you are able to do so at any stage. The data that is produced from the research will be kept in a locked cabinet at the University of Canterbury for a minimum of ten years.

If you agree for your child to take part in the research, please sign the consent form that is attached.

If you have any complaints you may contact the Chair of the University of Canterbury Ethics Committee. The contact details are given below.

If you have any questions about this project please feel free to contact Dr Laurie McLay: Phone (03) 369-3522 or, email: laurie.mclay@canterbury.ac.nz

Appendix D

Board of Trustees Consent Form

College of Education, Health and Human Development
 Phone: +63 027 213 7783
 Email: laurie.mclay@canterbury.ac.nz
 Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disorders

CONSENT FORM FOR BOARD OF TRUSTEES

This research has been assessed and approved by the University of Canterbury, Human Ethics Committee (HEC 2018/48).

- ☐ I/we consent to students and staff at Hohepa Hawkes Bay being included in the research project: “An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disabilities”.
- ☐ I/we have read and been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I/we understand what will be required of the research participants included in this project.
- ☐ I/we understand that the investigators do not foresee any potential risks to those participating in this study.
- ☐ I/we understand that all information about Hohepa Hawkes Bay and participating staff and students will be treated as confidential unless there is concern about anyone’s safety. In this case, a member of the research team will need to speak to someone else to ensure the safety risk is removed. No findings that could identify Hohepa Hawkes Bay or participating staff and students will be published.
- ☐ I/we understand that the findings of this study may be published in a research journal or at a conference and that the anonymity of Hohepa Hawkes Bay and participating staff and students will be maintained.
- ☐ I/we understand that participation in this project is voluntary and that we can withdraw from the project at any time without repercussions. I can also withdraw any data that has been collected at any time prior to the publication of that data.

- ☐ I/we understand that all research data that is collected will be securely stored at the University of Canterbury for a minimum of ten years.
- ☐ I/we understand that we are able to request a copy of the results of this research, should we wish to do so, and that these results will be provided.

Name: _____

Date: _____

Signature: _____

- ☐ I/we would like a summary of the results of this project.

Please return this form to Laurie McLay.

If you have any complaints you may contact the Chair of the University of Canterbury Ethics Committee. The contact details are given below.

If you have any questions about this project please feel free to contact:

Associate Professor Laurie McLay
Phone: (03) 369-3522
Email: laurie.mclay@canterbury.ac.nz

Appendix E

Staff Member Consent Form

College of Education, Health and Human Development
Phone: +64 027 213 7783
Email: laurie.mclay@canterbury.ac.nz
Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disorders

CONSENT FORM FOR STAFF

This research has been assessed and approved by the University of Canterbury, Human Ethics Committee (HEC 2018/48).

- ☐ I wish to participate in the project, “An investigation into the effectiveness of treatments for sleep disturbance in children developmental disabilities”.
- ☐ I have read and been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what will be required of myself and my child/the child in my care during this project
- ☐ I understand that the investigators do not foresee any potential risks to me or my child as a result of participating in this study. However, if the intervention results in an increase in stress, the staff working with us will provide support.
- ☐ I understand that all information about me will be treated as confidential unless there is concern about anyone’s safety. In this case my clinician will need to speak to someone else to ensure the safety risk is removed. No findings that could identify me or the child in my care will be published
- ☐ I understand that the findings of this study may be published in a research journal or at a conference and that the anonymity of the child in my care and I will be maintained
- ☐ I understand that participation in this project is voluntary and that I can withdraw from the project at any time without repercussions. I can also withdraw any data that has been collected at any time prior to the publication of that data

- ☐ I understand that all research data that is collected will be securely stored at the University of Canterbury for a minimum of ten years
- ☐ I understand that I am able to request a copy of the results of this research, should I wish to do so, and that these results will be provided for me
- ☐ I consent to others, listed below, being involved in the implementation of the intervention

Name: _____

Date: _____

Signature: _____

Others I consent to implementing intervention:

Name: _____

Name: _____

Name: _____

- ☐ I would like a summary of the results of this project.

Please return this form to Laurie McLay.

Appendix F

Parent/Caregiver Consent Form

College of Education, Health and Human Development

Phone: +64 027 213 7783

Email: laurie.mclay@canterbury.ac.nz

Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disabilities

CONSENT FORM FOR PARENTS/ CAREGIVERS

This research has been assessed and approved by the University of Canterbury, Human Ethics Committee (HEC 2018/48).

- ☐ I wish to participate in the project, “An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disabilities”.
- ☐ I have read and been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what will be required of myself and my child/the child in my care during this project
- ☐ I understand that the investigators do not foresee any potential risks to me or my child as a result of participating in this study. However, if the intervention results in an increase in family stress, the staff working with us will provide support.
- ☐ I understand that all information about my family will be treated as confidential unless there is concern about anyone’s safety. In this case my clinician will need to speak to someone else to ensure the safety risk is removed. No findings that could identify me or my child will be published
- ☐ I understand that the findings of this study may be published in a research journal or at a conference and that the anonymity of my child and I will be maintained
- ☐ I understand that participation in this project is voluntary and that I can withdraw my child or he/she can withdraw from the project at any time without repercussions. I can also withdraw any data that has been collected at any time prior to the publication of that data
- ☐ I understand that all research data that is collected will be securely stored at the University of Canterbury for a minimum of ten years

☐ I understand that I am able to request a copy of the results of this research, should I wish to do so, and that these results will be provided for me

☐ I consent to others, listed below, being involved in the implementation of the intervention

Name: _____

Date: _____

Signature: _____

Others I consent to implementing intervention:

Name: _____

Name: _____

Name: _____

☐ I would like a summary of the results of this project.

Please return this form to Laurie McLay.

Appendix G

Residential Manager Consent Form

College of Education, Health and Human Development
Phone: +64 027 213 7783
Email: laurie.mclay@canterbury.ac.nz
Date:



An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disorders

CONSENT FORM FOR RESIDENTIAL MANAGER

This research has been assessed and approved by the University of Canterbury, Human Ethics Committee (HEC 2018/48).

- ☐ I/we consent to students and staff at Hohepa Hawkes Bay being included in the research project: “An investigation into the effectiveness of treatments for sleep disturbance in children with developmental disabilities”.
- ☐ I/we have read and been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I/we understand what will be required of the research participants included in this project
- ☐ I/we understand that the investigators do not foresee any potential risks to those participating in this study.
- ☐ I/we understand that all information about Hohepa Hawkes Bay and participating staff and students will be treated as confidential unless there is concern about anyone’s safety. In this case, a member of the research team will need to speak to someone else to ensure the safety risk is removed. No findings that could identify Hohepa Hawkes Bay or participating staff and students will be published
- ☐ I/we understand that the findings of this study may be published in a research journal or at a conference and that the anonymity of Hohepa Hawkes Bay and participating staff and students will be maintained
- ☐ I/we understand that participation in this project is voluntary and that we can withdraw from the project at any time without repercussions. I can also withdraw any data that has been collected at any time prior to the publication of that data

- ☐ I/we understand that all research data that is collected will be securely stored at the University of Canterbury for a minimum of ten years
- ☐ I/we understand that we are able to request a copy of the results of this research, should we wish to do so, and that these results will be provided

Name: _____

Date: _____

Signature: _____

- ☐ I/we would like a summary of the results of this project.

Please return this form to Laurie McLay.

If you have any complaints you may contact the Chair of the University of Canterbury Ethics Committee. The contact details are given below

If you have any questions about this project please feel free to contact:

Associate Professor Laurie McLay will also be available to answer questions about this project:

Phone (03) 369-3522

Email: laurie.mclay@canterbury.ac.nz

Appendix H

Staff Knowledge Questionnaire

1. What is the estimated prevalence of sleep problems in children with developmental disabilities?

- a. 15-35%
- b. 35-50%
- c. 50-80%
- d. 80-90%

2. Which of the following is an example of a parasomnia:

- a. Night terrors
- b. Sleep onset delay
- c. Early morning wakings
- d. Co-sleeping

3. What is the name of the hormone that regulates our circadian rhythms?

- a. testosterone
- b. estrogen
- c. melatonin
- d. serotonin

4. What is the recommended sleep duration for a school-aged child?

- a. 6-7 hours
- b. 7-9 hours
- c. 9-11 hours
- d. 12-15 hours

5. What is the name of the watch-like device commonly used to assess and monitor sleep:

- a. electroencephalography
- b. polysomnography
- c. videography
- d. actigraphy

6. Which of the following is an example of an antecedent-based modification used to treat sleep problems:

- a. Extinction
- b. Graduated extinction

- c. Consistent bedtime routine
- d. Reinforcement/rewards

7. Which of the following are common functions of sleep interfering behaviour:

- a. social attention
- b. tangible
- c. escape
- d. all of the above

8. When using a faded bedtime procedure, a child's revised bedtime should be within how many minutes of their average sleep onset time:

- a. 5 minutes
- b. 15 minutes
- c. 30 minutes
- d. 60 minutes

9. True or false – sleep walking is an example of insomnia:

- a. True
- b. False

10. Antecedents are factors that occur:

- a. Before the behaviour
- b. After the behaviour
- c. At the same time as the behaviour
- d. All of the above

11. Which of these statements is true?

- a. Sleep is a behaviour
- b. Teenagers should get 7-9 hours of sleep a night
- c. Children with developmental disabilities show higher levels of sleep problems than typically developing children
- d. All of the above

12. Which of these strategies increases sleep pressure?

- a. Faded bed time
- b. Social story
- c. Video modelling
- d. Daytime naps

13. Which of the factors below can be associated with sleep problems?

- a. Non-compliance
- b. Obesity
- c. Unintentional injuries
- d. All of the above

14. Which of these factors can contribute to sleep problems in children with Autism Spectrum Disorder?

- a. Communication difficulties
- b. Difficulty adapting to change
- c. Challenging behaviours
- e. All of the above

15. Is sleep a behaviour?

- a. Yes
- b. No

16. Which of the following statements are true:

- a. Children may have the same sleep problem but the function is different
- b. Children may have different sleep problems but the function is the same
- c. One sleep problem may serve multiple functions
- d. All of the above

17. Sleep problems are caused by:

- a. Biological factors
- b. Psychological factors
- c. Social factors
- d. Behavioural factors
- e. All of the above

Appendix I

Staff Attribution Questionnaire

Read the following scenarios then indicate the extent you agree or disagree with the following statements

Antonio has ASD and is unable to communicate how he feels verbally, Antonio's parents say that he often resists and avoids their attempts to put him to bed at night by crying, having tantrums, and sometimes throwing items around the room when he is left alone. Antonio's parents will let him fall asleep in their bed before transferring him to his own bed later in the night.

Please indicate the extent to which you agree with the following comments:

	Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
It is likely to resolve WITHOUT treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is part of the child's natural sleep cycle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is part of the child's ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is learnt and can be changed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the parents change their responses the behaviour will change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Madi is a child with ASD who can verbally communicate her needs. It is often close to midnight before she falls asleep. She frequently wakes during the night for extended periods of time. During the day, Madi's parent's will often let her take naps because Madi says she is too tired. However, later in the night, her parent's struggle to get her to settle into bed on time because she says that she is no longer tired.

Please indicate the extent to which you agree with the following comments:

	Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
It is likely to resolve WITHOUT treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is part of the child's natural sleep cycle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is part of the child's ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is learnt and can be changed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the parents change their responses the behaviour will change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Tane has ASD and engages in repetitive/stereotypic behaviour in the form of rocking and humming. He is put to bed by his parent's at 7:30 p.m. but he is often found hours later still engaging in this behaviour. Tane's parents restore his sleep position, then sing lullabies and tell stories in order to help Tane go back to sleep, however when he wakes in the morning, he still appears to be tired.

Please indicate the extent to which you agree with the following comments:

	Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
It is likely to resolve WITHOUT treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is part of the child's natural sleep cycle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is part of the child's ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is learnt and can be changed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the parents change their responses the behaviour will change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Awhina has ASD. She is doing very well at school but sometimes runs home during the day to tell her mother her worries. At night she calls for her mother repeatedly but will not get out of bed because she is afraid of the dark. Awhina's mother goes to her repeatedly over the evening to reassure her. She herself is exhausted so sleeps in her child's bed so they can both "at least get some sleep".

Please indicate the extent to which you agree with the following comments:

	Strongly disagree	Disagree	Somewhat agree	Agree	Strongly agree
It is likely to resolve WITHOUT treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is part of the child's natural sleep cycle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is part of the child's ASD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This behaviour is learnt and can be changed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If the parents change their responses the behaviour will change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix J

Sleep Diary Template

	Date:	Monday:	Tuesday:	Wednesday:	Thursday:	Friday:	Saturday:	Sunday:
Daytime	Setting (where fell asleep)							
	Time asleep							
	Time awake							
Night-time sleep	Setting (where fell asleep)							
	Time put to bed							
	Frequency of Curtain calls*							
	Curtain calls after put to bed (Describe each)							
	Your responses to each curtain call (Describe each)							
	Best estimate of time asleep							
		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

1 st Night time awakening	Time & Duration of awakening	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins
	Behaviour while awake (Describe)							
	Your responses (Describe)							
	<div></div>							
		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
2 nd Night time awakening	Time & Duration of awakening	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins
	Behaviour while awake (Describe)							
	Your responses (Describe)							
	<div></div>							
		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

3 rd Night time awakening	Time & Duration of awakening	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins	_____ mins
	Behaviour while awake (Describe)							
	Your responses (Describe)							
<div style="border-top: 1px dashed black;"></div>								
Time awake in the morning								

*Curtain calls: Any bids for parent attention (e.g. crying out) between the time of being put to bed and falling asleep

Notes:

Appendix K

Assessment Psychometric Results

Table 2

Results from Psychometrics Administered During Assessment

Measure	William	Steven	Harry
CSHQ	44	45	N/A
SDSC	39	47	N/A
ASHS	N/A	N/A	4.5
VABS (Age Equivalent)			
<i>Receptive</i>	1 Year 11 Months	Returned incomplete	0 Years 8 Months
<i>Expressive</i>	0 Years 1 Month		0 Years 0 Months
<i>Written</i>	Less than 3 Years		Less than 3 Years
GARS	86	48	104
CBCL			
<i>Internalizing Symptom Score</i>	57	68	66
<i>Externalizing Symptom Score</i>	61	76	61
<i>Total Score</i>	62	76	71
SDQ	25	21	24
PedsQL			
<i>Psychosocial Score</i>	66.67	53.33	43.3
<i>Physical Health Score</i>	100	71.88	40.63
	<i>T</i> = 40	<i>T</i> = 40	
MASC	(Within average range)	(Within average range)	Returned incomplete